

EVALUATION OF THE SASKATCHEWAN BREAST CANCER NETWORK'S
COLLABORATION PROGRAM TO PROMOTE HEALTHY LIFESTYLES

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By

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ABSTRACT

Introduction: Over ten years ago the Saskatchewan Breast Cancer Network (SBCN) was created to work towards better meeting the needs of breast cancer patients and survivors in the province. With funding from the Cancer Program of the Public Health Agency of Canada in June 2009, the SBCN implemented the *A Thinking, Learning and Caring Collaboration: Promoting a Healthy Lifestyle* program in various communities throughout Saskatchewan.

Purpose: The purpose of this study was to evaluate the program implemented in 2009/2010 to: (1) determine to what extent the program was implemented as proposed; and (2) assess to what extent the program met its own goals.

Methods: Using a constructivist ethnographic mixed methodology, the data collected included self-report surveys, observational data, and semi-structured interviews, which were conducted with seven members of the Advisory Committee and five breast cancer survivors representing urban, rural, senior, young and Aboriginal demographics. Descriptive analysis was used to tabulate the surveys' results and qualitative analysis followed the structure of the program logic model.

Results: The results of this evaluation reveal that the program was implemented as proposed despite unforeseen challenges, which necessitated slight alterations in the timing of events. The program was successful in meeting many of its goals; however, the sustainability of these impacts are unlikely due to the disintegration of the formal Network following the completion of the program.

Conclusions: Future research should focus on the role of current medical service providers and grassroots organizations in meeting the needs of breast cancer survivors, beyond treatment for physical symptoms. Evidence surrounding the motivations to adopt healthy choices will facilitate effective program delivery for the diverse group of Canadian breast cancer survivors.

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In loving memory of Aaron Laufer, z"l (1981-2008)

With all my heart, I wish you could have seen me finish, the last thing you knew I had started

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1. INTRODUCTION

1.1 Breast Cancer in Canada

Pink ribbons, jewelry and key chains have become social representations of breast cancer support and awareness. Although they represent a cultural departure from the negative stigma historically associated with the disease, this awareness may be superficial. While significant media coverage and fundraisers focus on fighting breast cancer, little mainstream attention is paid to the health of survivors after diagnosis and treatment, despite it being the most common type of cancer among Canadian women.¹ In 2009, breast cancer was diagnosed in an estimated 22,700 women in Canada, with an additional 5,400 deaths among women from the disease that same year.¹ This heightened incidence of the diseases is also seen in Saskatchewan, with an estimated 630 new cases diagnosed in the province in 2009.¹

Less than three decades ago the prognosis was grim; 50 percent of women diagnosed with breast cancer died within five years after diagnosis.² However, since 1986 the breast cancer death rate has fallen by more than 30 percent and is currently the lowest it has been since 1950.¹ Today 87 percent of Canadian women diagnosed with the disease live past the five-year survival mark.¹ Although these women survive the physical symptoms of cancer, the journey often does not end with the end of clinical treatment.

According to the National Cancer Institute³, this ongoing experience is referred to as survivorship, which “covers the physical, psychosocial, and economic issues of cancer, from diagnosis until the end of life [and includes] family members, friends, and caregivers [as] part of the survivorship experience.” This definition offers much needed attention on the time after the clinical illness, as the current survival rates for breast cancer are remarkable with about two-thirds of the women diagnosed becoming survivors. As of 2005, almost 148,542 of all living Canadian women had been diagnosed with breast cancer in the previous ten years.¹

As survivorship steadily increases, more women are living with the long-term side effects of breast cancer treatment.^{4,5} While an extensive body of research exists surrounding the experiences of diagnosis and treatment of breast cancer, little evidence is available recounting the experience of patients as they transition into survivors. There is a significant need for information at all stages of breast cancer so that effective methods of support can be made available, especially for the steadily increasing group who are surviving.

1.2 National Breast Cancer Initiatives

In Canada there are many advocacy and research organizations that provide information and support for cancer, and specifically the breast cancer community. The many groups that address all types of cancers, as well as those that focus on breast cancer, are present throughout the country and include: Breast Cancer Society of Canada, Canadian Breast Cancer Foundation, Canadian Breast Cancer Network, Provincial Cancer Agencies, Canadian Breast Cancer Research Alliance, Cancer Advocacy Coalition, Breast Cancer Action [province], Willow Breast Cancer Support Canada, Canadian Partnership Against Cancer, and Canadian Cancer Society. Mandates of the organizations range from funding breast cancer research, to advocacy and networking. There is some overlap between these organizations, and at first glance it is not easy to distinguish the various roles they play in their communities.

Of the many organizations in the Canadian cancer community, one of the most well known cancer organizations is the Canadian Cancer Society, widely known for their door-to-door daffodil sales as a fundraising initiative. With a mission to eradicate all types of cancer and improve the quality of life of those touched by cancer, this national volunteer- led, community based organization works in five key areas: research, advocacy, prevention, information and support.⁶ To meet the needs of patients, survivors, clinicians and researchers faced with many different types on cancer, the Canadian Cancer Society partners with various national organizations to better meet the needs of patients, survivors, and communities alike. As well, they have ten offices in larger centres across the province.

Health Canada and more recently the Public Health Agency of Canada have been involved in supporting and strengthening connections between breast cancer community initiatives across the country. One such group is the Canadian Breast Cancer Network (CBCN), who with the support of Health Canada became a registered charity in November 1994. The CBCN is the survivor-directed link between the various concerned groups and individuals in the breast cancer communities nationally. Since its inception it has grown markedly with partner organizations across the country, including the Saskatchewan Breast Cancer Network.⁷

1.2.1 Model for National Collaboration

In 2007, Canadian Breast Cancer Network had their capacity building model titled *Model for National Collaboration* evaluated. A report was produced and provided perceptions and

recommendations, which were reached by interviewing network coordinators nationally and reviewing administrative documents. This network included “hundreds of local, provincial/territorial, regional and national organizations, including public sector, not-for-profit organizations, and grassroots groups.”⁸

The *Model for National Collaboration* evaluation found that participants at the local, level experienced numerous benefits of connecting with a network of breast cancer related stakeholders. The benefits included: validation of work, increased ability to attract partners and funding, efficient and effective communication, new member orientation, and the facilitation of knowledge exchange.⁸ This evaluation also found that most respondents felt that the model was in line with their goal to “provide highly credible, timely, quality and useful materials to women diagnosed with breast cancer and their families.”

Although there were stated benefits, funding to network participants was reduced, which limited the ability to widely implement the model. It was clear that being a member of a national network gives strength to communities that would otherwise be ill equipped to deal with meeting the needs of breast cancer patients and survivors. This model focused on the networking benefits for stakeholders, but did not discuss the benefits of a national network in information and support for breast cancer survivors. This omission provides a prime example of how the needs of breast cancer survivor’s are underrepresented in a society that is geared towards diagnosis and clinical treatment.⁸

By not including those with the lived experience of cancer in the evaluation process, the gap in meeting the needs of breast cancer survivors is perpetually widened as these essential components of breast cancer program development are commonly overlooked in the research. Throughout the literature, there is evidence to suggest the value of community participation for prevention, screening and treatment of cancer, while little evidence is available on networking survivors.⁹ It is clear the health behaviours and lifestyle education are vital for the quality of life of these individuals, but to date few opportunities exist.

1.3 The Saskatchewan Breast Cancer Network

The Saskatchewan Breast Cancer Network (SBCN) is “a collaboratively managed and developed initiative dedicated to improving access to breast cancer information and support” in the province.¹⁰ Founded in 2000 to fill the need of breast cancer patients and survivors alike in

Saskatchewan, the organization has a history of over ten years, increasing awareness and access to breast health/breast cancer education and information. Upon its inception the SBCN outlined its three main goals, and they remain the same today. These are: (1) to establish and maintain an effective network between individuals and organizations concerned with breast cancer in Saskatchewan; (2) to ensure people living with breast cancer in Saskatchewan receive accurate and current information in a timely manner; and (3) to ensure people living with breast cancer in Saskatchewan have access to support services in all regions, in a timely manner.¹⁰

Originally hosted by Breast Cancer Action Saskatchewan (BCAS), a change in project funding in 2004 and reliance on volunteers led to the disintegration of the formal Network. At the mercy of available funding the SBCN was limited to consecutive short-term projects in order to accomplish its mandate of connecting communities around breast cancer awareness and information. In 2006, the Canadian Cancer Society committed to sponsoring the Saskatchewan Breast Cancer Network as a community of like-minded partners working to increase awareness and access to breast health and breast cancer education, information and support for those concerned with breast health and breast cancer throughout the province.¹¹ The SBCN Advisory Committee was re-established in the fall 2006 with the goal of promoting healthy lifestyles among breast cancer survivors and the public of Saskatchewan. As host, the Canadian Cancer Society submitted the proposal for the current program to the Public Health Agency of Canada on behalf of SBCN.

The current program run by the SBCN was funded by the Cancer Program of the Public Health Agency of Canada in June 2009. With this funding the SBCN implemented the *A Thinking, Learning and Caring Collaboration: Promoting a Healthy Lifestyle* program, developed to build on past successes and increase awareness and access to breast health and cancer education, information and support. The new direction of this program included expanding the focus to risk reduction and early detection for all cancers.

In order to guide this program, the SBCN identified an expert Advisory Committee made up of key informants and stakeholders throughout the province. The SBCN Advisory Committee membership represented the following: Canadian Cancer Society, Les & Irene Dubé Centre of Care (Breast Health Centre), Saskatchewan Cancer Agency, Saskatoon Health Region, Breast Cancer Action Saskatchewan, research community representatives and breast cancer survivors.¹¹

The current program was implemented with the intention of promoting a change in self-

reported and externally perceived survivor understanding and knowledge of how to lead a healthy lifestyle to help determine the effectiveness of the information gained in the current program. Improving the public's awareness of the needs of breast cancer survivors as well as increasing the community's attendance at SBCN events was another intended outcome of the current program. Finally, making national connections, increasing stakeholder presence at events and increasing the perception that the SBCN brings together people working in breast cancer and advocates for them were to be achieved.

Under the guidance of the SBCN Advisory Committee, the program was facilitated by the SBCN Program Coordinator and Canadian Cancer Society (CCS) Program Coordinator to work towards realizing the three main objectives on the program. The first objective was to ensure that all breast cancer survivors have access to and knowledge of risk reduction and early detection of all cancers throughout the province, regardless of their age or location (i.e. rural or urban). Overall, this objective aimed to build awareness of breast cancer survivors of how to lead a healthy lifestyle by inviting them to attend educational events. The second objective was to increase public awareness of risk reduction and early detection strategies for all cancers. By leveraging connections in the breast cancer community and learning from them, the SBCN addressed the healthy lifestyle education and information needs within Saskatchewan.¹¹ The third objective was to enhance the SBCN's role in facilitating collaboration among key stakeholders. The events and activities of the current program made it possible for the SBCN to connect and communicate with the breast cancer community in a collaborative and sharing environment.¹¹

Towards achieving these goals, the SBCN proposed to establish collaborations with Health Regions and smaller urban centres, organize and run two community based Think Tanks, implement educational events, and develop and disseminate educational resources. Through this program the SBCN hoped to not only network the breast cancer community and identify barriers for leading a healthy lifestyle for survivors, but also to raise awareness of the role of the SBCN as an effective networking organization in Saskatchewan.

As part of the funding agreement, the SBCN was required to submit a final evaluation of the program to determine whether their objectives had been met. To meet this requirement, Dr. Anne Leis was approached, as she is the Dr. Louis Schulman Chair in Cancer Research and professor in the Department of Community Health and Epidemiology at the University of Saskatchewan. This initial relationship between the Department and the SBCN led to the

adaptation of the evaluation into a Master's thesis. The current study will evaluate the *A Thinking, Learning and Caring Collaboration: Promoting a Healthy Lifestyle* program to determine whether the intention of the SBCN's proposal was realized.

1.4 Objectives of Evaluation

The overarching objective of this evaluative research is to assess whether the program implemented by the SBCN has met its own goals, as were previously outlined. More specifically, the objectives of the current evaluation were as follows:

- 1) To determine to what extent the program proceeded as proposed
- 2) To assess to what extent the program met its own goals

Assessments were primarily conducted within the four components determined pivotal in the program: (1) information; (2) networking; (3) education; and (4) support.

2. LITERATURE REVIEW

In order to provide some context for the evaluation, the review of the literature explored themes such as breast cancer survivorship, health and lifestyle behaviours of cancer survivors and the role of support groups and grassroots organizations such as the SBCN in meeting the needs of survivors. For the purposes of this literature review, the scope of the search did not solely look at breast cancer, but broaden the exploration to other cancers as many of the needs of cancer survivors may be similar and yet this may foster a greater appreciation for the experiences of all cancer survivors. For this evaluation, a review of the literature was performed by accessing the various online journal databases. Experts in the areas of cancer research, qualitative research and program evaluation, who were members of the supervisory committee, identified additional studies and books.

The first section of this chapter discusses breast cancer survivorship and how Aboriginal, rural, young and senior cancer survivors experience this. Additionally, it highlights the role of the health care system in meeting the needs of cancer survivors. The second section reviews the health and lifestyle of cancer survivors, specifically related to their increased health risks and behaviours. In the final section of this chapter, the role of support groups, networks and community-based organizations are outlined.

2.1 Breast Cancer Survivors' Needs

The National Coalition for Cancer Survivorship, the first survivor-led cancer advocacy organization in the United States, defines survivor from “the time of diagnosis and for the balance of life, a person diagnosed with cancer is a survivor. This definition includes those whose lives have been touched by cancer; family, friends and caregivers.”¹² Survivorship means much more than surviving the physical symptoms of cancer but encompasses the experience of these individuals as they live with, through, and beyond a diagnosis of cancer.¹³ This recognition of the psychosocial process of survival is strikingly different from the traditional and clinical definition of survivors as a person who has been “disease-free for at least five years after treatment.”¹⁴

The increase in cancer survivorship and in research about the topic attests that the successes in early detection and treatment enable an increasing number of people to survive and

lead healthy lives.¹⁵ As survivorship steadily increases, more women are living with the long-term side effects of breast cancer treatment, impacting their daily lives.^{4, 5} Narrative research paints a picture of the resilience of cancer survivors after dealing with the tolling experience of treatment.¹⁶ While a substantial body of research exists regarding the experiences of diagnosis and treatment of breast cancer, little evidence is available surrounding the experience of patients as they transition into survivors. The limited literature that does address the after treatment trends, focus on relapse surveillance while the need to assist individuals in transitioning from patient to survivor is overlooked.⁹

The available research primarily constructs survival as a return to health and normalcy; of going back to the way things were prior to diagnosis.² This simplifies the personal changes that occur after a cancer diagnosis and overlooks the new challenges women only begin to face after completing treatment. These personal changes are caused by transition, which is a recurrent theme throughout the limited literature on cancer survivorship. The personal changes throughout the stages of survivorship force survivors to adjust their definitions of themselves and their relationships.¹⁷ These changes have been found to lead to increased anxiety, and are further compounded by feelings of unmet needs in consultations with oncologists.¹⁸

The transitory period of breast cancer survivorship is a trying experience, in which relief and celebration of survival are coupled with the demands of ongoing physical and emotional symptoms, changes and threats.¹³ It is established that medical professionals often interact with breast cancer survivors during follow-up consultations, however little evidence exists in the literature exploring communication processes specific to non-physician providers.⁴ This is significant, as many survivors will continue to seek out health information and support throughout the remainder of their lives from non-clinically based organizations. Transitioning from patient to survivor has been cited a significant process for the physiological well-being of people who have battled cancer; however there is insufficient research available on how this period of psychological change is reflected by changes in communication with the health care practitioners and professionals. It is therefore important to determine the way for these survivors to communicate with their information providers whether they are doctors or community based initiatives.

Finding accurate and accessible information sources can be difficult for many survivors creating a need for more research on the values of networking for accessing the skills, tools, and

information required to transition from a breast cancer patient to a survivor. The literature purports the importance of initiatives geared towards promoting and advancing translational survivorship research to improve the quality of care provided to cancer survivors.⁹

In a study conducted by Cappiello et al.¹³ in the United States, 20 women with a median age of 52 who had been diagnosed within the past five years and had completed therapy were interviewed. This study was carried out as part of a larger project to support women in adapting self-care as cancer survivors. This study found that survivors experience a lack of information offered by medical staff upon completing their treatment.¹³ It was further suggested by participants in this study that there was a need to receive information beyond the last treatment appointment, well into their transitory period of being a survivor.

Despite the clear need for continual information sharing, this opportunity to provide information may not be realized. This is especially disheartening considering evidence that women may be especially open to receiving such information during this transition. In a pilot study, Lethborg and Kissane¹⁹ found that women described themselves as being more prepared to ascribe meaning to their experience after completing breast cancer treatment, than they were earlier in the process.¹⁹ This study included 35 women between the ages of 35 and 77 who were taking part in a Post Adjuvant Treatment Support Program (PATs), a short-term group in which participants reviewed their experience of diagnosis and treatment. As many women do not feel emotionally ready to process the impact of breast cancer on their lives until after they have completed treatment, it is especially important that supports are heightened during this phase.¹⁹

Many women describe feeling the least supported during a time when they would be the most receptive and in need of the information. Therefore it is clear that the issue does not necessarily lie in a lack of information on post-treatment health, but rather in the pathway of this information as a means of supporting survivors to manage their symptoms and to adjust to life after cancer treatment.¹³ It is essential that health care providers capitalize on the teachable moment that surviving cancer provides in an effort to encourage patients to actively aim for better health.²⁰

Cancer survivorship is a lifelong adjustment, which includes an increased risk of future health concerns as evident in literature.²¹ As these individuals' needs continually evolve it is essential to constantly revisit and update programs in order to best meet their needs. As part of a comprehensive model of care there is a need to address and treat the health of the whole person,

however the current model generally doesn't extend beyond surveillance for recurrence.¹⁹ A surveillance model of care overlooks many of the concerns survivors will face throughout their lives and is rarely developed or discussed with the survivor, and survivors risk being lost to follow-up.²¹ While the support of the health care system may not always be available for breast cancer patients once their clinical treatment is completed, this practice of dismissal is not founded in evidence that survivors do not require it. The following section will discuss in further detail research that is available pertaining to the support needs of cancer survivors and the capabilities of the health care system to meet these needs.

2.1.1 Special Population Needs

Aboriginal Cancer Survivors. Minority populations differ in their cancer outcomes due to varying social determinants of health. These include socioeconomic status, environmental exposures, and access to resources and medical professionals.²² One such affected group is Aboriginal women, who experience a disproportionate burden of illness compared to both Aboriginal men and non-Aboriginal Canadian women.²³ While disease tends to be described by symptoms, survivorship can be characterized by an individuals' cultural identifiers, including race and ethnicity.²²

Aboriginal women, one such identifier, are at a higher risk for breast cancer attributed in part to poor screening rates. In fact, only 22% of First Nations women's in 2002 reported having had a mammogram in the past 12 months.²⁴ This is a significant number of Canadians given that as of the 2001 Canadian census, 3.3% of the population identified themselves as Aboriginal, which includes North American Indian, Métis, or Inuit.²⁴ In Canada, all women between the age of 50 and 69 are encouraged to get regular screening and in a recent population health survey, 62% of women in this age group reported having been screened in the past two years.^{25, 26}

To facilitate minority participation in cancer survivorship programs, racial and ethnic disparities in health care need to be monitored, understood and eliminated.²² By developing culturally sensitive environments and sustaining participation, the limited participation of minority groups in cancer survivorship initiatives, can be addressed.²² However, research has found that Aboriginal people's experiences are neglected.²³ Not only must Aboriginal women be included in programs, but they also require culturally tailored information in order to encourage

applying cancer risk information to their realities.²⁴

In their recent study in Saskatchewan, Poudrier and Mac-Lean²³ interviewed twelve Aboriginal women between the ages of 42 and 75 and asked them provide photographs with explanations depicting their cancer experience. The women reported that Aboriginal healing rituals and ceremonies were important aspects of cancer prevention and treatment, yet were often not recognized or accepted by doctors. Such natural treatment choices include herbs and healing circles.²⁴ It is of great importance that health care providers understand the role of traditional beliefs and values in Aboriginal healing.²³ However, it is important to be aware that even within cultural minority groups, there is still much diversity in the experiences of each woman, as well as similarities with members of other cultural groups of survivors. This was highlighted by Aboriginal breast cancer survivors who spoke about the need to highlight differences in experience and treatment along with the similarities among the group.²³ The photovoice method, which consists of using photographs as a way to share experiences, is a valuable way to empower minority populations to share stories. Research has found that for Aboriginal cancer survivors, storytelling is a key medium for sharing cultural information across generations as well as an effective mode of education.²⁴

Rural Cancer Survivors. Limited research is available on the needs and experiences of rural women, or on their experiences specific to breast cancer survivorship.²⁵ This may be in part due to challenges conducting research with rural populations that are sparse and widely distributed geographically.²⁷ The limited research conducted on the psychological and physical changes of rural women associated with breast cancer survivorship has made it difficult to identify the support needs of this community and assess whether these needs are being met.^{25, 28}

Underserved populations, such as survivors living in rural communities, may have more challenges accessing information, resources and support than those living in urban centres.²⁷ While available research has not found any differences in the occurrence of or experience with symptoms, it is supported that rural Canadian women with breast cancer have considerable unmet needs, such as access to information and services.^{25, 27}

Not only are their needs not being met, but also these needs may differ from those living in urban communities. In a review of the literature of rural breast cancer patients, it was suggested that rural breast cancer patients might actually require more support and health-related

information.²⁸ This could be in part attributed to the unique stresses of rural women with respect to the demands of traditional gender roles, greater stigmatization and less privacy in their personal life due to small communities.²⁸ While Canadian urban centres provide a wealth of resources, programs and services to help women meet their information and support needs, this is not the case for women living in rural and northern areas.²⁵ In a study by Gray et al.,²⁵ 276 rural women from communities across Canada took part in a project by the CBCN to learn more about their experiences with cancer. Researchers found that many Canadian rural breast cancer survivors identified “becoming aware of and/or gaining access to health care information, support and services” as a key theme in rural survivorship. Women were often disappointed about the types and levels of services offered locally or regionally, and they often compared their situations negatively with urban women. These themes of information, support and services presented in Figure 1, closely reflect the goals of the SBCN’s program.

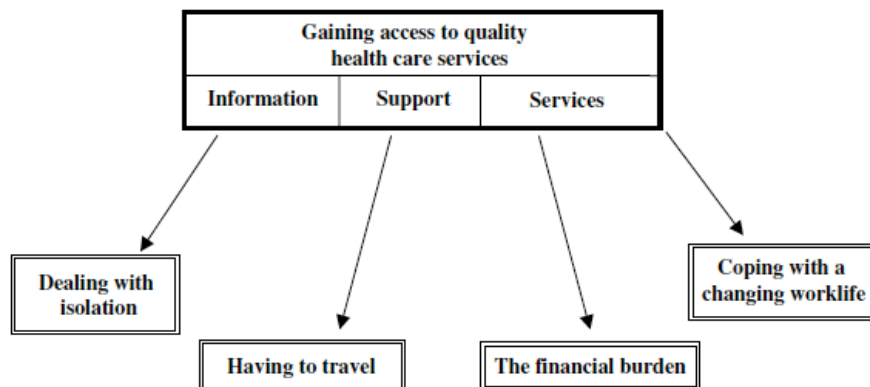


Figure 1 Conceptual Framework of Distinct Rural Themes.²⁵

By the very nature of living in a rural community, these women are likely to have to travel significant distances to reach breast cancer treatment and services. This travel makes rural breast cancer patients confront additional social and economic costs from which their urban counterparts are exempt.²⁸ These costs can continue to pose additional challenges for rural breast cancer survivors. Rural survivors are also faced with additional challenges such as low economic status, scattered population, and limited availability of healthcare providers and healthcare facilities.²⁷ Such challenges may be related to reported higher level of helplessness and

hopelessness among rural survivors in coping with breast cancer compared to urban survivors.²⁵

Age and Cancer Survivorship. Breast cancer primarily affects older women, with only a quarter of the cases occurring in women under 50 years of age.²⁹ This proportion of cases is reflected in the literature, which focuses primarily on older, post-menopausal women.^{14, 29} While many of the needs of cancer survivors are irrespective of age, some factors such as lifestyles, responsibilities and developmental stages vary throughout the lifespan. The literature that has been conducted on younger populations has found that while many of the needs are shared across these two groups, younger survivors experience more age specific needs than do older women.¹⁴ As the number of younger women diagnosed with breast cancer in recent years has increased, there is a clear need for research that focuses on the needs of younger survivors.²⁹ As incorrect assumptions may be made when applying research conducted on older women to younger populations, age specific data is very much needed in order to deliver effective programs and services.¹⁴

There is some evidence to suggest that the age of the patient is related to their emotional response. One study found that older women tend to report less distress about breast cancer than younger women.² This could perhaps be due to more experience dealing with crisis that women with shorter life histories. Regardless, it is important to understand the role age plays on the perceived barriers for living a healthy lifestyle so promotion activities can be geared accordingly. Clinical evidence has found that a greater distress is associated with diminished immune response and early relapse of breast cancer.¹⁷ Therefore the consequence of diminishing such feelings among survivors is in fact in the best interest of patients and their health care providers.

The ongoing tribulations faced by many breast cancer survivors tend to reflect their stage in life and include financial, social, health and psychological difficulties. However, older women are at a higher risk of age-related illness, which potentially presents these survivors with an additional burden in respect to each of the aforementioned factors.²⁷ Co-morbidity of other illnesses in an aging population of breast cancer survivors presents more challenges than for younger women who are generally in better health prior to diagnosis. This is supported by studies that have found that older people report worse quality of life and worse physical functioning than younger people surviving cancer.³⁰ In fact, the likelihood of poor health is almost five to ten times what would be expected in the general elderly population.²⁷ This is

complicated by a decreased information seeking behaviour from medical establishments with increasing age.⁴ Therefore it is essential for community-based organizations to provide accurate health information to these women that they are not receiving it from clinical providers.

Although poor health disproportionally affects the physical well being of the elderly, younger women are faced with greater challenges in their psychological recovery. A study conducted by Ganz et al.²⁹ found that the youngest group of women, diagnosed between 25 and 34 years of age, had significantly poorer emotional and social functioning as well as lower levels of energy than women their age without breast cancer. These psychosocial issues have increasingly been researched, finding that older survivors have better emotional functioning and less psychological distress than younger survivors.^{14, 29, 30} It has been hypothesized that this “emotional resiliency” in older women could be due to their greater capacity to cope with the diagnosis, developed over the longer course of their lifetime.²⁹ Conversely, with more of their lives ahead of them, younger women may perceive breast cancer as more disruptive. This threat leads to poorer mental health outcomes that continue to persist years after diagnosis.^{29, 30}

Younger age at diagnosis also means different long term concerns and outcomes related to recovery from treatment. As screening is promoted only for women over the age of 50, most young women are not diagnosed at an early stage. Because of the late stage diagnosis, more aggressive cancer and denser breast tissue, younger women are often given more toxic treatments, making them more vulnerable to long-term treatment effects.³¹ These late effects of treatment are more emotionally disruptive in the lives of younger survivors.²⁹ One study found that this deficit was still seen one year after the diagnosis of breast cancer in predominantly younger women.³⁰ Younger women do not expect their lives to be interrupted by illness, are in the peak of the career and may be caring for young children or aging parents. Older women may have fewer of these responsibilities and thus adjust their lifestyle with greater ease. By not being able to work, younger women are also faced with a significant financial burden that can have long-lasting effects, compared to women who are closer to retirement.¹⁴

The developmental stage of younger women also suggests significant physiological differences, specifically being pre-menopausal. Breast cancer treatment sometimes results in early-onset menopause, which can have a lasting impact on fertility, body image and sexuality.¹⁴ For women who intend to have children this can be devastating. Furthermore, early onset menopause can lead to greater risks for sexual dysfunction.²⁹ Such reproductive health outcomes

may contribute to changes in emotional well being.²⁹

Many young breast cancer survivors feel isolated, as there is limited age-appropriate support services and information that address the aforementioned concerns of this population.¹⁴ There remains limited research on how all the physical, social and informational needs are differently met by women who are older compared to those who are younger. Although research has been conducted on the differences in treatment for younger breast cancer patients, there is little evidence regarding the psychosocial needs of young breast cancer survivors.¹⁴ This area of research is only recently gaining momentum, which still leaves a significant gap in the literature given the current likelihood of young women surviving cancer and their present day needs.

Health Care System Role and Support. When breast cancer patients complete their treatment, many experience the loss of their safety net; the end of systematic check-ups, regular health surveillance and social support.⁵ Given that many survivors do not have any clinical symptoms of illness, it is difficult for health care professionals to warrant ongoing care indefinitely.¹⁸ Those breast cancer survivors, who are able to discuss ongoing concerns with their health care providers, report that they do not understand their concerns or ignore their complaints.⁴ Not only do survivors experience challenges with finding ongoing medical support throughout this transition period after treatment, but those who make contact experience a disconnect with medical personal who had previously been very involved in their health regime. As many of the concerns faced by breast cancer survivors lie outside the boundaries of recurrence surveillance, these issues are dismissed by the health care system.

Such feelings are supported throughout the literature as a psychological component to the transition from a patient to a survivor that may affect long-term success and quality of life.¹⁸ Research has found that a significant number of women manage to cope with the process of treatment, but then find it challenging to adapt to a loss of intensive medical support.¹⁹ This difficult shift in coping would not be something to hide, but when women in remission do not behave as though the cancer is in fact over, one study found that the positive regard for the accomplishment of survivorship is then withdrawn.² This shocking evidence highlights the need for research to provide evidence for the usefulness of ongoing support from the medical community beyond the presence of physical symptoms.

Although patients with a current cancer diagnosis may have access to many health resources and clinicians, they may not receive the same quality of care in remission. This attention is dedicated to those with chronic medical problems during active cancer treatment and surveillance.⁹ Despite these practices, it has been shown that overall health may be as important as cancer specific concerns. For example, research suggests that psychological predictors of coping with cancer may be useful in designing support programs for patients, and may be applicable for survivors.³² Initiatives to improve the quality of care provided to cancer survivors have become a priority of survivorship advocates and policy makers, despite the limited number of organized and comprehensive programs that are currently in place.⁹

Instead of dismissing ongoing concerns, this sensitive transition period is a window of opportunity for health care professionals to encourage healthy behaviours. The time after completion of treatment may present a crucial opportunity to capitalize on women's motivation to pursue behavioral goals related to health, which is currently not being maximized by the health care system.⁵ Instead the current model of health care delivery seems to be set up to deal with symptoms of current illness and not to prevent future illness.

Follow-up care is complicated by the multiple risk factors that pose further health complications for cancer survivors. There is a clear value in ongoing surveillance of survivors in order to identify and reduce potential long-term health risks among this population. A significant body of knowledge exists regarding outcomes for survivors up to two years after treatment while under intense surveillance. However once follow-up care is shifted from clinical staff to community health care professionals, little research about what happens to cancer survivors exists.¹⁶ This results in inconclusive evidence for practices regarding screening and risk-reduction methods for cancer survivors, who are particularly in need of these services.³³

Complicating the need for follow-up care is the commonly cited challenge of ensuring that their primary healthcare providers have the most recent information about cancer-related health risks.³³ Research has found that physicians are proponents of disseminating the message of “cancer’s overness” to survivor patients and provide evidence that a survivor’s health status is no longer a priority concern for oncologists.² Such a limitation of the medical system makes it difficult for women to find support as they navigate their way from being a healthy individual, to a patient, to a survivor.¹⁹ While narratives have documented survivors’ ongoing uncertainty about life, few studies have been able to quantify the construct.¹⁴ Although doctors may try to

convince people in remission that their cancer is in the past, many survivors experience stress and anxiety stemming from the constant fear of recurrence.¹⁴

Psychosocial issues are often experienced well after cancer treatment, and many survivorship advocates have vouched for the broadening of care to encompass such concerns.⁹ Although the romanticized notion of the “battle” of cancer leading to a “victory” in the face of an overwhelming “assault” are common in the cancer repertoire, cancer is not a war and these euphemisms overshadow the daily challenges of a cancer survivor. In fact, one study found that breast cancer survivors did not feel that their survivorship was an accomplishment as “getting through cancer was not an achievement”, with no prize other than their life.² The metaphor of illness is made evident through this language, and the need remains to shift this paradigm away from terms affiliated with fighting and towards therapy and coping.³⁴

It is clear that while chemotherapy, radiation, and surgery diminish the physical symptoms associated with cancer, treatment needs to target coping mechanisms, perceptions, feelings and overall well-being. In the holistic sense, cancer does not stop when the physical symptoms disappear; a more profound overall psychological change is required. Throughout the literature there is a clear differentiation between health care workers who treat illness and those who treat cancer. The tangibility of the physical symptoms of cancer provide an excuse for medical professionals to not provide overall holistic treatments for cancer patients and survivors, in an overwhelmed system where practitioners seem to always be looking for the simplest and quickest solution.

2.2 The Health and Lifestyle of Cancer Survivors

Although survivors overcome the clinical symptoms of breast cancer, they continue to be at risk for a myriad of other illnesses well beyond their initial period of remission and surveillance. While research has traditionally focused on the risks of recurrence, secondary cancers, and treatment effects, there has been a recent shift towards studying the health behaviours of survivors.³⁵ For example, genetic susceptibility and the toxicity of treatment means that survivors need to be extra careful when it comes to their health behaviours in order to reduce risks such as secondary cancers.^{20,33,36} The research on cancer survivorship is only beginning to gain momentum, so limited studies exist on associated longer-term physiological outcomes.²⁰ This leaves the ‘who, what, where and how’ of optimal care delivery largely unanswered.³⁷

Lifestyle changes are important to prevent negative health outcomes among breast cancer survivors. Well-established risks for breast cancer survivors are mirrored by recommended healthy behaviours for the general public. As cancer survivors are at an increased risk of recurrence, adherence to these positive behaviours needs to be further encouraged among this specific group. Research has found a link between obesity, cancer recurrence and a reduced quality of life in breast cancer survivors; significant evidence to support healthy weight management efforts in this population.²⁰ Achieving a healthy weight through physical activity also has positive effects on psychological or emotional well-being as well as for strengthening bones, especially important for women who lose bone density with increasing age.²⁰ Denmark-Wahnefried et al.²⁰ summarize key messages that should be targeted to survivors to reduce the aforementioned risks and include: (1) primary prevention messages (i.e. healthy diet); and (2) secondary prevention strategies (i.e. screening).

Many survivors make the necessary lifestyle changes not only to improve their health outcomes, but also to cope with their cancer experience and feel like they are regaining control over their health.³⁸ Compared to the general population, it is evident that breast cancer survivors lead relatively healthy lifestyles. For example, a population-based study from the United States found that breast cancer survivors were 42 percent more likely than non-cancer controls to engage in vigorous physical activity.³⁵ Specifically, a report from The Agency for Healthcare Research and Quality³⁵ cited physical activity as a way to improve a cancer survivors' psychosocial health. The importance of including physical activity in a healthy lifestyle is especially important for breast cancer survivors who are at an increased risk for co morbid illness due to weight gain, changes in body composition, decreased physical functioning, and bone loss.³⁸

A population-based intervention conducted by Bellizzi et al.³⁵ found that only 13 percent of cancer survivors in a stratified sample of 7,384 adults across the United States continued to smoke after diagnosis, significantly less than the non-cancer controls. However, in a review of the literature on long-term health behaviours of adult cancer survivors since 1966, quite contrary results were reported, with a quit rate of only four percent noted among smokers with breast cancer.²⁰ Even more recently a US study was conducted with 58 breast cancer survivors (median age 56) and 29 first-degree relatives of survivors (median age 46), who completed both a survey about behaviour risk reduction strategies for cancer as well as a follow-up interview. Equally

disheartening, the study found that 50 percent of cancer survivors who smoked prior to diagnosis continue to smoke after treatment.³⁶ Although comparisons of survivors to population control groups seem encouraging, it may be misleading to only compare survivors with members of the general public who have not had cancer. It is important for cancer survivors to improve their health behaviours compared only to their previous lifestyle choices.

Research shows that 50 percent of breast cancer survivors consume fewer than the recommended five servings of fruits and vegetables per day, 23 percent consume more than 30 percent of their calories from fat, and 28 to 43 percent lead sedentary lifestyles.³⁶ A study conducted by Bellizzi et al.³⁵ found that 67 percent of breast cancer survivors engage in routine exercise after treatment. They are even more likely to engage in positive health behaviours such as exercise and routine screening tests (i.e. mammograms and pap smears) than non-cancer controls. This particular study is interesting considering that the non-cancer controls were first-degree relatives of the survivors who could have been personally impacted from the cancer diagnosis, and more likely than the general public to improve their health behaviours. However, since this study focused on participants of higher economic and educational backgrounds, both groups may have had fewer barriers to accessing healthy activities.

A need exists for more research including diverse populations to gain a better understanding of what barriers exist for people of varying socio-economic statuses. The need for representing diversity in the research is also essential in the growing literature on the relationship between physical activity and quality of life in cancer survivors. Though this relationship is increasingly represented in the literature, racial and ethnic effects need to be recognized in order to effectively offer support to all survivors.³⁹ Additional research is needed to fill the gaps where a broad demographic population has not been represented. Such research would be especially significant to apply to a province like Saskatchewan, where much of the population lives outside many city centres and therefore do not have access to much of the same information and services as their urban counterparts.

Data regarding motivations for behaviour change among cancer survivors is poorly represented in the literature, and an unmet need for behavioral interventions exists.¹⁵ While potential benefits of lifestyle interventions specifically within survivor populations need to be further explored in the research, the promotion of a healthy weight through a low-saturated-fat diet with ample amounts of fruits and vegetables and moderate levels of physical activity is

currently recommended.²⁰ Without being aware of these significant driving forces to make healthy life choices it will be difficult for health promoters to address areas of contention and develop strategies aimed at encouraging positive choices for breast cancer survivors.

A review of the literature of health behaviours after cancer diagnosis found that only approximately 20 percent of oncology care physicians provide assistance in promoting behaviour changes.²⁰ Providers may be in the best position to offer evidence of the relationship between behaviour modifications and improved quality of life, which may provide incentive to adopt healthy lifestyles.³⁹ As depicted in the model created by Denmark-Wahnefried et al.²⁰ in Figure 2 below, it is clear that all these aforementioned behaviour modifications are preventative strategies for a range of health concerns affiliated with surviving various types of cancers.

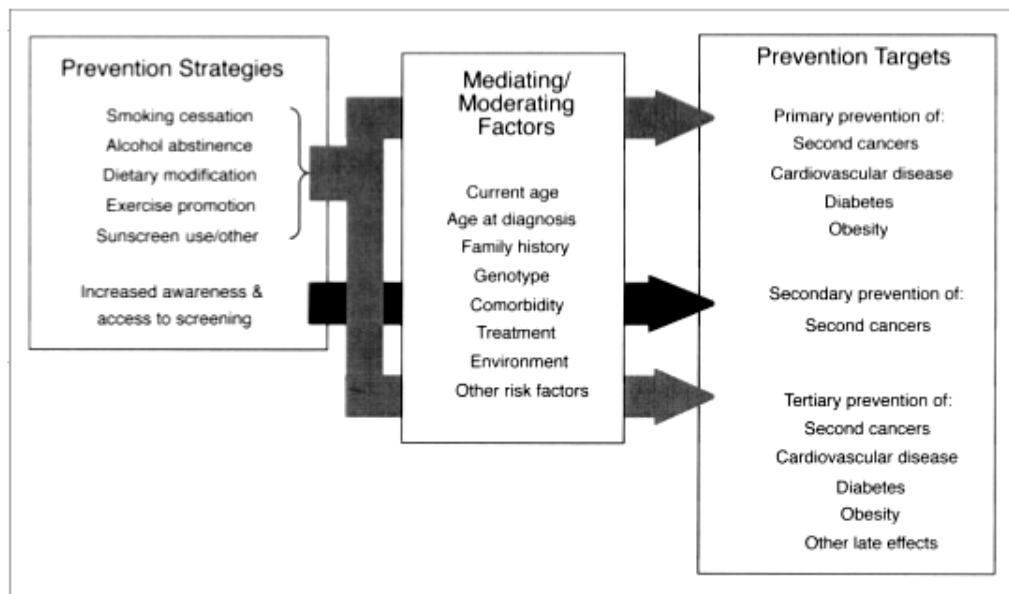


Figure 2 Model for Preventative Health Among Cancer Survivors.²⁰

Although many cancer survivors are motivated to adopt healthy lifestyles, there is a need for more research to understand how these decisions are made.³⁸ Diagnosis with breast cancer may not be enough incentive for a woman to adopt a healthy lifestyle. In a study conducted by the Miriam Hospital and Brown Medical School, breast cancer survivors who believed that a negative health behavior was a factor in developing cancer, were more likely to report behaviour changes.³⁶ While an individual may need to believe that they can help improve their quality of

life, studies of programs interventions to empower patients and survivors remains scarce in the literature.

2.3 Role of Support Groups, Networks and Community Based Organizations

Cancer impacts the broader social circle of the individual who is diagnosed, and is not suffered by the diagnosed alone. As the health care system emphasizes outpatient care, support groups have become increasingly important for breast cancer survivors, putting the onus on family caregivers to assume tasks previously carried out by health care professionals.^{16,40} However this support system is not available to all survivors, as many people do not have someone available to actively provide this kind of care, and may be subjected to adverse outcomes. A study conducted by Kroenke et al.⁴⁰ found that socially isolated breast cancer survivors were at an increased risk of mortality, specifically when they lacked close relatives, friends, or living children.

During the 1990s, many support groups sprang up around the world, including those that involved women with different stages of breast cancer. These support groups were led by individuals with various professional credentials, in various settings, and were of various program lengths.⁴¹ The benefits of support groups have been found to be both clinically and statistically significant. For example, many studies of group support for people affected by metastatic breast cancer, have identified psychological benefits, particularly improvements in mood and pain control.⁴¹ Therefore, it may be advantageous for clinicians to assess women's social networks to help determine the extent of available resources and to help ensure access to necessary care.⁴⁰

While there is clearly evidence to suggest the role support groups have on long term health outcomes of survivors, questions still remain as to which interventions are best, who is most likely to benefit, and how long these programs should run to attain maximum benefits.⁴¹ Especially when it comes to addressing many of the non-physical concerns affiliated with cancer, these groups target a broader range of concerns experienced throughout survivorship.

As many survivors become more health conscious after successful therapy, it is up to the community-based health groups to take advantage of this opportunity to encourage survivors to meaningfully change their health behaviours.⁹ In a study of 47 recent breast cancer survivors Allen et al.⁵ found that these women felt that post-treatment interventions to target their new

health concerns needed to target the needs of living in remission. Specifically, the areas they felt needed to be addressed included: providing information about the physical, emotional, and social issues, enhance coping strategies, stress reduction techniques, and methods for soliciting social support, and opportunities to exchange social support with other survivors.⁵

There is a significant amount of evidence in the literature to suggest the value of community participation for prevention, screening and treatment of cancer, while little evidence is available on networking survivors.⁹ It is clear that health behaviour and lifestyle education is vital for the quality of life of these individuals, but to date few opportunities exist. This oversight in cancer education is significant particularly as initiatives to partner with organizations in the broader community and emphasizing a participatory approach is a pillar of the origins of health promotion.

The first World Health Organization (WHO) conference on health promotion produced the Ottawa Charter for Health Promotion, the purpose of which was to address the key principles of health promotion, being “to achieve a greater balance between curative and preventive services, and to ensure that health professionals fully appreciate the social and environmental causes of ill health.”⁴² Though it is disappointing that the system cannot support the needs of the population, it is encouraging to find that many small initiatives are aware of the needs of survivors beyond treatment and work diligently to address these concerns.

Health promotion initiatives typically emphasize community collaboration and partnerships in shaping intervention approaches and building community capacity.⁴³ Breast cancer prevention includes reducing harmful behaviours such as smoking and consuming alcohol as well as increasing healthy behaviours such as physical activity and cancer screening. These health promotion activities may play a key role in controlling the adverse long-term consequences of cancer and treatment.³⁵ Research has shown that women’s psychosocial adjustment to breast cancer is significantly correlated with frequency of communication about cancer, the honesty of communication about cancer, being encouraged by a partner to talk about cancer, and the manner in which unpleasant topics are discussed. Conversely avoidance of such discussions is associated with increased depression and lower wellbeing.¹⁷

Partnerships between community organizations and health promotion departments provide the foundation for achieving core public health functions.⁴⁴ It is the values shared by these groups, such as collaboration, democratic participation, power sharing, solidarity, trust, and

reciprocity, which promote citizen participation in the implementation of local health promotion programs and initiatives.⁴⁵ For example, one review of the literature found that the public discourse specifically on survivorship was an active theme in the cancer support community.² Unfortunately, studies conducted about such collaborations tend to define social support as the functional and structural support, but not based on the needs of the patient.³⁴ Just as the current program functioned as far as being implemented with the coordination structure in place, the value of the content of a program cannot be assessed based on its mere existence.

Social networks alone are not enough to promote recovery as research has found that marriage for example may actually be a predictor of ill health in women.³⁴ Peterson et al.³⁴ found that participatory, inclusive and reciprocal support measures create a social system, which can significantly affect health outcomes. It is therefore evident that the ways social support networks are established and delivered may have a significant impact on the effectiveness of their messages.

3. METHODOLOGY

3.1 Study Design

The goal of the current study is to evaluate a networking and education program run by the SBCN designed to improve access to health information and increase understanding of the unique challenges and perceived barriers of urban, rural, young, and senior breast cancer survivors towards making healthy lifestyle changes. The methodological framework of the current study utilized a mixed method design which includes a constructivist ethnographic analysis of the qualitative data. A combination of various data collection methods included interviews, surveys, researcher observations as well as immersion and observational notes, as will be detailed subsequently.

The benefit of using multiple data sources and a mixed methodology was to enhance the depth of information the researcher was able to obtain. Collecting data from a variety of individuals in the Network led to a better understanding of how this program was envisioned, developed, executed and received.

3.1.1 Constructivist Rationale

Many socially constructed concepts exist in understanding the meaning of health and well being. Even Western medicine's prevailing metaphor of "medicine is science" is socially constructed as it serves to institutionalize and standardize healthcare.³⁴ This construct also de-emphasizes the role that individual health behaviours play in overall well being, and creates a sense of helplessness as disease is constructed as an external factor that attacks people from the outside and for which medical treatments provide the best solution. When a lack of control is attributed to health, individuals may feel like there is little they can do to improve their quality of life, which had already been shown to be an incorrect assumption in the literature.

Women are labelled as cancer patients by the medical system; sometimes even before experiencing the associated symptoms.³⁴ It is this same system that then abruptly removes this label once the cancer is gone, though this often does not mean that the experience of cancer is over for the individual. Responses of individuals to emotional processes such as a changing identity from patient to survivor are constructed and classified within the dominant paradigm of clinical pathology.⁴⁶ Interpreting the discourses of breast cancer survivorship reveals that

knowledge and meaning are constructed based on survivors' interactions within a larger social context.

The term constructivism refers to how individuals construct their world and was used in the conceptual framework of the current study.⁴⁷ Guided by the program goals, this approach was chosen to reveal how breast cancer survivors perceive and make meaning of survivorship and the trials that go along with it. The proposal submitted by the SBCN defined the constructivist approach of this evaluation as indicators included measures of perception, terminology that is evocative of a constructivist paradigm. Additionally the constructs of support, networking, information and education can mean different things to different people, and it is essential to understand how these are interpreted before being able to effectively offer these services.

Illness has been identified in the literature as a cultural metaphor, one which breast cancer survivors construct.³⁴ By analyzing both the personal experiences of breast cancer survivors as well as their reflections on their participation in the SBCN's program, a greater understanding of how concepts of health, illness and barriers are interpreted can be attained.

As has been evident throughout the research, there tends to be an overemphasis on the need to label the patient's experience. Emotions associated with survivorship transitions are pathologized into classifications of explicit illness.⁴⁶ For women diagnosed with breast cancer, the meaning of this experience is not clinical but is rather constructed by their unique interpretations of their realities. Therefore, the literature needs to further explore the socially constructed meanings of healthy lifestyle, social support, transitions, and barriers associated with survivorship through the shared experiences of breast cancer survivors using a constructivist lens.⁴⁸

3.1.2 Ethnographic Rationale

Quantitative methods are often regarded as the gold standard in psychological research, but are actually just a single narrative with "no wider claim to truth than any other little narrative."⁴⁶ Much of the traditional research on breast cancer focuses on empirical data collected using only a quantitative methodology, which is certainly a limitation in the robustness of the data. More recently, a shift towards survivorship research has been accompanied by a growing number of studies focusing on the shared experiences of cancer patients and survivors. There is a need for additional qualitative cancer care research that expresses the journey of

survivorship instead of focusing primarily on the clinical facts.⁴⁶

The ethnographic approach is a qualitative design that focuses on an entire cultural group, or subculture, and seeks to understand how individuals make sense of their learned values, behaviours and beliefs.^{49,50} It has been used to both “elicit the participants’ point of view and to understand their world.”⁵¹ This balances deeper examination of certain aspects of the participants’ experience while maintaining a sense of the overall program. This approach was an excellent fit with the current program evaluation as it provided an ideal way of encompassing the lives of the culture-sharing group of breast cancer survivors in Saskatchewan.

The culture of cancer survivorship is unique in a province like Saskatchewan with a diverse and dispersed population. In order to assess how event participants and facilitators of this particular program interpreted or developed shared patterns of behaviour or understanding, a description of experiences would not suffice. Instead it was essential for the evaluation to uncover how all members of this group regarded their situation, social interactions and themselves through their participation in the current program.⁵² The events and activities attended by participants represented the natural environment of these women, as it was not set-up by the researcher. Additionally, they offered an ideal opportunity to collect participant observations, a primary research tool in ethnography.⁵⁰

As the program developed by the SBCN involves a cultural group and outlined goals that could only be determined by encouraging self-reflection and sharing personal experiences specific to elements of the program, ethnography was the best choice of methodology for this study. Choosing a qualitative component in the current study allowed the evaluation to proceed in a way that a strict quantitative study would not permit. Given that different people construct emotions, beliefs, challenges and feelings differently, using a qualitative methodology afforded participants the freedom to express whatever they experienced without being limited by arbitrary boundaries.

3.2 Program Logic Model Development and Use

The term *logic model* gained popularity in quantitative and qualitative evaluations in the 1970s when it was used by Joseph Wholey in his book *Evaluation: Promise and Performance*, published in 1979.⁵³ In early use, Wholey emphasized the use of theory for program evaluability assessments, whether a program was ready to be evaluated.⁵⁴ Logic models are excellent tools

for translating the needs of a population into programs as they provide a comprehensive and visual representation. These models continue to be adapted according to their increasing use in evaluation work, creating a framework for designing and monitoring.^{55,56} Ideal for use in program evaluations, the logic model describes what the program intended to do as it relates to the implementation of the program's planned events and activities.⁵⁷

It is not enough to declare that the program was implemented, but rather to continuously monitor progress in order to identify and measure the outcomes.⁵⁸ Not only does a logic model help to establish a program framework, but it can also help to ensure the longevity of the program. For example, in a study of logic model use for a rural breast cancer program, developing an effective and accurate logic model was highlighted as contributing to a sustainable program.⁵⁶

In order to effectively carry out this evaluation, a logic model was developed to map out the complex relationships between communities, survivors, and key stakeholders in the context of program activities run by the SBCN. The type of logic model developed in this study was an activities approach model, which links the activities together to map the process of program implementation.

For the current study, the development of the logic model began when the student researcher became involved with the program. The framework for the first draft was based solely on the program proposal that was created by the SBCN. This proposal outlined the three main objectives of the program, expected outcomes and activities, and an evaluation plan. The proposal submitted by The Canadian Cancer Society on behalf of the SBCN outlined key pillars, which guided the organization of the logic model in Figure 3 below. The SBNC Coordinator had spent many years working in the breast cancer community and her implicit knowledge of the needs of survivors was integral to the development of the proposal. However, as a researcher new to the breast cancer community, it was essential to explicate this knowledge in a systematic way to facilitate the evaluation. This transfer of knowledge is a key function of developing a logic model and greatly supports this program evaluation.⁵⁸

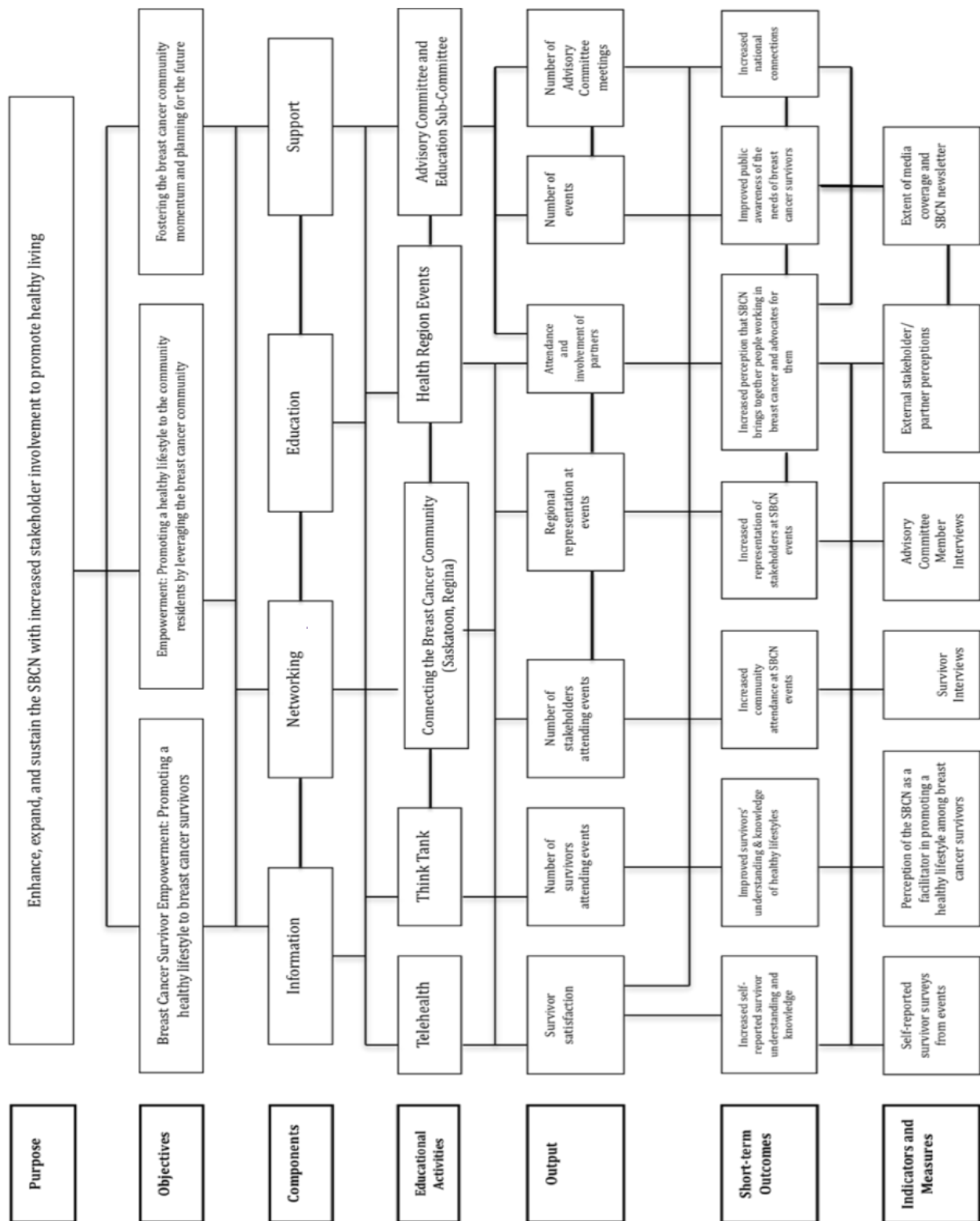


Figure 3 Program Logic Model.

Moving forward, discussions between the student researcher and research supervisor led to revisions and a greater understanding of the relationship between the goals of the program and the events as well as the differences between program outcomes and outputs. Further discussion involved both researchers and the SBCN Program Coordinator who was able to further specify the relationship between each of the events, the components, intended outcomes and goals of the program. By this point in the revisions, the program was well under-way throughout the province and the researchers were able to become specific as to which indicators would be best used in order to measure the outcomes. Finally, the program logic model was presented to the Advisory Committee for feedback and was then finalized.

The intention of this program was to build upon past successes of the SBCN and continue to increase the awareness and access to breast health and breast cancer education and information. This was to be done by expanding the focus of previous programs beyond breast cancer alone; to encompass efforts related to risk reduction and early detection for all cancers. The use of logic models allows program managers to conceptualize health promotion and risk reduction approaches more clearly and design programs accordingly.⁵⁵ However, the usefulness of a logic model is based on how accurately its indicators measure whether the goals of the program have been met.

The three overall expected outcomes of the current program included: (1) an increased understanding of education needs specific to breast cancer survivors; (2) an increased public awareness of cancer risk reduction strategies; and (3) continued collaboration within the breast cancer community.¹¹ These goals and their associated inputs and outputs are visually depicted in Appendix A. In a logic model, as well as in the implementation of a program, the outcomes should drive the events and activities instead of the other way around.⁵⁸ This logic model was jointly developed by SBCN and the researchers based on the program proposal submitted to PHAC. The goals and indicators outlined in the program proposal were captured as intended inputs and outputs. Based on the implementation of these events as part of the overall program, the SBCN intended to see the following output determined using the data collected from the events. These outputs include: (1) survivor satisfaction; (2) number of survivors attending events; (3) number of stakeholders attending events; (4) regional representation at events; (5) attendance and involvement of partners; (6) number of events; and (7) number of advisory committee meetings.

By including outputs in the model, the relationships between all the program components, outputs and outcomes are clearer.⁵⁵ This allows evaluators to determine whether each level of the logic was actually satisfied by the implementation of the program. Furthermore, due to the significant conceptual overlap in the relationship between activities and events and outcomes, building a logic model allows the evaluator to independently assess the contribution of each of the components to the overall program.

Activities were carried out by the SBCN according to these four components as previously detailed. These activities took place over the course of a year throughout the province and include: Think Tank, Telehealth, Connecting the Breast Cancer Community, Health Region Events, Advisory Committee Meetings and Education Sub-Committee Meetings.

By utilizing data collected from conference participants as subsequently outlined, it is possible to determine whether the short-term outcomes of the program have been met. These outcomes are as follows: (1) increased self reported breast cancer survivors' understanding and knowledge; (2) improvement in public awareness of the needs of breast cancer survivors; (3) increase in attendance of the community at SBCN activities; (4) improved survivors' understanding and knowledge of healthy lifestyles; (5) increased representation of stakeholders at SBCN events; (6) increased perception that SBCN brings together people working in breast cancer and advocates for them; and (7) increased national connections.

3.3 SBCN Program Promotion and Dissemination of Resources

The SBCN and Network partners promoted events for the current program through several different mediums. The Program Coordinator offered personal invitations and additional e-mail announcements, which were disseminated to the breast cancer community network contacts including agencies and institutions represented on the advisory committee. It was also sent to the Canadian Cancer Society Peer Support Program, comprised of survivors who are connected to Cancer Connection Population Health Promotion departments in each health region, partner organization announcements, phone calls to survivors and paid advertising.

Following the completion of the current program the SBCN committed to sharing all relevant documents, information newsletters and resources created by this project on an ongoing basis with the Public Health Agency of Canada, project partners, survivors, consultants, SBCN members, and all external interested parties through the well-established Network pathways. The

information shared included reports, event results and resources developed for the program. The specific SBCN partners included: the Saskatchewan Cancer Agency, Saskatoon Health Region, BCAS (and included in their membership newsletter and website), Canadian Cancer Society (included in their website and peer support system), HOPE Cancer Help Inc., Women's Mid-Life Health Centre of Saskatchewan, First Nations Inuit Health Branch, Canadian Breast Cancer Network, SBCN and Women and Cancer Advisory Committees. Resources were disseminated by the SBCN to an extensive list of stakeholders included in Appendix B.

This information was disseminated by mail, newsletter articles, teleconference calls, website postings, presentations, and abstract submissions. PowerPoint Presentation slides used at events were mailed electronically or in hard copies as requested. Additional and subsequent information and educational resources were distributed via mail, e-mail submission of newsletter articles, teleconference calls, posting on websites, presentations, and submission of abstracts.

3.4 Events and Activities

Over the course of the SBCN's program, various educational activities were developed and facilitated in various health regions throughout Saskatchewan. Each activity is mapped in the logic model according to its purpose towards reaching the overarching goal of the SBCN program. Below, Table 1 summarizes the events and activities, followed by more detailed explanations in chronological order. The intended outcomes and audience as well as the topic of the event are included.

Table 1. Summary of Events and Activities.

| Event Type | Event Name | Location | Date |
|--------------------------------|---|--------------------------------------|---|
| Survivor Think Tank | <i>Thinking, Learning, Caring</i> | Saskatoon | September 18, 2009 |
| | <i>Aboriginal Women and Cancer</i> | ----- | March 11, 2010 |
| Telehealth | <i>Natural Health Products and Breast Cancer</i> | Saskatoon (broadcast to 11 sites) | October 1, 2009 |
| Conference | <i>Connecting the Breast Cancer Community</i> | Saskatoon | December 4, 2009 |
| | | Regina | March 12, 2010 |
| Health Region Events | <i>Connecting the Cancer Community</i> | Prince Albert | October 28, 2009 |
| | <i>Nutrition and Cancer: Reducing Risk of Cancer and Recurrence</i> | Battleford | March 5, 2010 |
| | | Prince Albert | March 16, 2010 |
| | | Saskatoon | March 19, 2010 |
| | | Rosetown | March 29, 2010 |
| | <i>Making Healthy Choices: Reducing Risk of Cancer and Recurrence</i> | Estevan Weyburn | March 23, 2010 |
| Advisory Committee | N/A | Saskatoon | October 30, 2009 November 9, 2009 January 22, 2010 February 23, 2010 |
| Education Sub-Committee | N/A | N/A | N/A |

3.4.1 Survivor Think Tanks

Survivor Think Tanks were small, informal and intimate information sharing sessions. Think Tank events aimed to engage participants in general guided conversations to encourage the sharing of personal experiences and meaning of being a survivor.

Thinking, Learning and Caring. The Survivor Think Tank titled, *Thinking, Learning and Caring: TLC Think Tank* was held in Saskatoon on September 18, 2009. Although there was no Aboriginal representation as was originally planned due to last minute cancellations, this one-day workshop drew survivors representing young, senior, urban and rural participants who contributed to the day's discussion and sharing.

In order to identify challenges and barriers in leading a healthy lifestyle, post-it notes were used to document personal experiences. In groups of four survivors, these challenges were written on the post-it notes and placed in one of five categories: rural, urban, young, senior, all. That is, which category best represented the group who is most challenged by the barrier towards leading a healthy lifestyle. These groupings of post-it™ notes were collected after the event and common themes have been identified. Other notable conversations and happenings were also independently documented at these events by the researcher for future analysis. This final

component of the data was organized according to barriers and challenges faced by four different groups. These groups of breast cancer survivors are: urban, rural, young, and old. While certain aspects of survivor's cancer information and networking access were common among all groups, it is of interest to note what differs amongst these groups. This data was compiled into a Survivor Recommendation Document (Appendix C) by the SBCN Program Coordinator.

Aboriginal Women and Cancer. This five-hour workshop held on March 11, 2010 gathered thirteen Aboriginal breast cancer survivors. The event planning, promoting and facilitating was co-chaired by two Aboriginal breast cancer survivors with support from the SBCN program coordinator. This event was designed to respect Aboriginal breast cancer survivors' ownership over their own stories by making it an Aboriginal-driven session. Given the first opportunity to share their experiences with breast cancer, this event was intended to increase receptiveness to accessing and discussing health information education. Towards this goal, a Talking Circle was implemented to promote inclusiveness and to draw out Aboriginal survivors' input regarding their needs and concerns about adopting a healthy lifestyle, among other topics.¹¹ This data was compiled into an Aboriginal Survivor Recommendation Document (Appendix D) by the SBCN Program Coordinator.

3.4.2 Telehealth Education Session

The Telehealth Education Session titled, "Natural Health Products and Breast Cancer" was filmed at Royal University Hospital on October 1, 2009 and broadcast across the province to 11 sites or individual communities. Colleen Olson, who is a pharmacist working at the Saskatoon Cancer Clinic, was the speaker for this session.

3.4.3 Connecting the Breast Cancer Community

Two Connecting the Breast Cancer Community events took place; one in Saskatoon on December 4, 2009 and one in Regina on March 12, 2010. These events were designed to promote SBCN, connect the breast cancer community to services and resources, facilitate networking of the network and facilitate connecting breast cancer survivors. The agenda for these events included messaging surrounding leading a healthy lifestyle consistent with the goals of the current program. Also, the *Making Healthy Lifestyle Choices Questionnaire* was

disseminated and collected from all those participants who wished to take part.

3.4.4 Health Region Events

By collaborating with Health Regions when possible, the SBCN was able to engage communities throughout Saskatchewan to promote and/or facilitate local educational events.

Connecting the Cancer Community. On October 28, 2009 The Prince Albert Parkland Health Region hosted this event in Prince Albert. “The agenda included a message of promoting a healthy lifestyle along with connecting participants to health region representatives.”¹¹

Nutrition and Cancer: Reducing Risk of Cancer and Recurrence. Identified at the Survivor Think tank as an area of concern that required more attention, a series of sessions addressing nutrition and cancer were arranged. These two-hour education sessions were designed and developed with a power point presentation by public health nutritionist and breast cancer survivor Heather Drozd. These events were held on the following dates: (1) March 5, 2010 in Battleford; (2) March 16, 2010 in Prince Albert; (3) March 19, 2010 in Saskatoon; and (4) March 29, 2010 in Rosetown.

Making Healthy Choices: Reducing Risk of Cancer and Recurrence. These community education events were designed to reach a wider audience, used a PowerPoint presentation and were facilitated by the Canadian Cancer Society’s Cancer Control Coordinator. These two *Making Healthy Choices: Reducing Risk of Cancer and Recurrence* education events occurred in the south east part of the province in collaboration with Sun Country Health Region and took place on March 23, 2010. In Estevan, the “Lunch and Learn” event was held followed by an evening “Coffee and Dessert” event in Weyburn.

3.4.5 Advisory Committee

An Advisory Committee was assembled by the Coordinator of the Saskatchewan Breast Cancer Network for the purpose of networking key stakeholders in the province towards enhancing collaboration and effectively delivering the goals set out in the program proposal. The advisory committee consisted of members who represented the following organizations: The

Canadian Cancer Society, Saskatchewan Breast Cancer Network, Les & Irene Dubé Centre of Care Saskatoon (Breast Health Centre), Saskatchewan Cancer Agency, Saskatoon Health Region, Breast Cancer Action Saskatchewan, HOPE Cancer Help Centre, the University of Saskatchewan and two breast cancer survivor representatives.

Committee meetings attended by the student researcher took place on the following dates: (1) October 30, 2009; (2) November 9, 2009; (3) January 22, 2010; and (4) February 23, 2010.

3.4.6 Student Researcher's Role

As an evaluator of the current program, I was invited to join Advisory Committee meetings as an observer. During these meetings I gained a greater understanding of the dynamics of the Committee, relationships between various stakeholders working in women's cancers in Saskatchewan, as well as challenges faced in the facilitation of the current program. During these meetings I was also able to get to know the members of the Committee and develop familiarity, which would facilitate making contact to conduct interviews. At these meetings I was also offered information that would not have been known to general participants at events, which I also attended. This opportunity helped me construct my interview questions for the Advisory Committee members, as I was aware of successes and challenges of the program as they arose. This, I believe, allowed me to conduct more concise and targeted interviews as well as create a comfortable environment for Advisory Committee members as they shared their experiences with someone with whom they were familiar.

As participant observation is a key research tool in ethnography, I took notes at each of the events I attended. There was no premeditated method to this note taking, and it allowed me to reflect on how those around me interacted with each other, with myself, and how I felt being immersed in the culture of breast cancer survivors at the SBCN's events. These notes will not be systematically included in the analysis, but offer important reminders as to how I interpreted the behaviours of survivors and stakeholders at the time of the events. My role in these settings was to be close to the events' participants, while maintaining my role as a researcher. I identified myself as "observer as participant", as I revealed my role as researcher to other participants but limited my interactions with them in the event setting.⁵⁰

As a researcher, I was quite invested in the information being shared at events and was not able to emotionally detach myself from the participants I was observing. Just prior to

beginning this work, a very close friend of mine was diagnosed with Non-Hodgkin's Lymphoma. I found it challenging to sit through many of the events, especially those in which survivors candidly shared some harsh truths about their experiences – perhaps ones that I wasn't emotionally prepared to hear. I believe that this personal experience translated into compassion for and solidarity with the women who took part in the events run by the SBCN. I also gained a greater understanding of the significance of the efforts of the Advisory Committee. I felt as if I had a vested interest in learning about what my friend was going to go through, as many experiences are not unique to breast cancer survivors, but shared by survivors of all different cancers.

3.4.7 Education Sub-Committee

As part of the current program, the SBCN established an Education Sub-Committee called *The Education Working Group* as “a means to ensure scope and quality of activities and products respecting the needs of target population and goals of project.”¹¹ This group included a broad range of breast cancer representatives throughout the province. This group included SBCN Advisory Committee members, senior, rural, young and Aboriginal breast cancer survivors, Health Region representatives, a registered nurse and a physiotherapist.

3.5 Measurements and Indicators

Measurements and indicators are predetermined ways of establishing whether an objective has been met. In order to assess whether the current program met its own objectives, measurements and indicators were established as per the program logic model previously outlined in Figure 3. To measure and determine whether the goals of the program were met, interviews were conducted with survivors who attended the events and with members of the SBCN Advisory Committee, which included: key stakeholders, network partners, SBCN staff, and breast cancer survivors. This provided an indication of any changes in beliefs or behaviours directly related to the funding and implementation of the current program. Additionally, self-administered questionnaires and the researcher's observations painted a fuller picture of the extent of impact the program has had on the intended audience. The questions asked on the self-report surveys developed by the SBCN, were used in the current evaluation as indicators to measure: improvements in survivors' understanding and knowledge, improvements in

understanding of healthy lifestyles, increased attendance at events of stakeholders and community members, perception of the SBCN as an advocate and improved public awareness of the needs for breast cancer survivors. In addition to the previous indicators, these interviews measured national connections, which were established at the Advisory Committee level. These measures and indicators are summarized below in Table 1.

Table 2. Evaluation Measures.

| | | | | |
|---------------------|--|---|--|--------------------|
| Qualitative | Survivor Interviews | Advisory Committee member interviews (including Program Coordinators) | Perception of the SBCN as a facilitator in promoting a healthy lifestyle among breast cancer survivors | Researcher's notes |
| Quantitative | Self-reported survivor surveys from events | | | |

3.6 Population and Sample Selection

The participants in the current study were women from across Saskatchewan who were already involved in the current program as Advisory Committee members or attended at least one of the many events that took place across the province. The individuals who attended the program events represented a wide age range and a mixture of urban and rural settings, as events were held in many different communities. There was no requirement to be a breast cancer survivor to attend an event, and newly diagnosed patients, family members, friends and the community at large were encouraged to take part. Among survivors, the events were not geared at those who had gone through certain treatments and thus participants could have experienced many different combinations of chemotherapy, surgery, hormone replacement therapy, and radiation therapy. Some had relapsed while others are still in remission, and the time since their first diagnosis varied amongst the group.

As already mentioned, participants of community events, Telehealth and ThinkTanks were recruited by the SBCN through direct invitation, e-mail announcements through the Saskatchewan Breast Cancer Network community, partner announcements, phone calls to survivors and paid advertising throughout the province. All the people who had attended an event were given the opportunity to complete a survey at the end of the event, which were

collected by the SBCN. Though some men were present at events, all the breast cancer survivors contacted for interviews were women. These women had attended at least one event and represented the key demographics of the current program as outlined in the program proposal: young, senior, rural and urban. The procedure used for recruiting interviewees will be discussed in the next section.

3.7 Procedure

3.7.1 Quantitative Data Collection

The quantitative component of the study was carried out by the SBCN Program Coordinators in consultation with the researchers. Surveys developed by the SBCN were handed out at each event and collected at the end of the activity including: Think Tanks, Telehealth events, learning events and conferences taking place throughout the province. Survey data were collected at all community-based events run by the SBCN. The surveys were developed by the SBCN as the program unfolded. For example, new questions were added along the way and some questions were omitted. Data collected from these events were valuable but not necessarily able to be combined, which resulted in a fluctuating number of answers for the various questions. Questions with a low response rate or those not directly relevant to the evaluation were discarded.

Although everyone was encouraged to participate, survey completion was not a requirement of event participation nor attendance. As it turned out, most of the participants did choose to fill out the evaluation survey. This provided the researcher with concise information about the attendees such as the number of people who attended these events, how effective they believed these events were, and how useful the information was to them.

For Telehealth events, surveys were sent out to Telehealth sites throughout the province at the same time as promotional resources were distributed for the lecture. Following the speaker, these surveys were collected from all locations across Saskatchewan and mailed to the SBCN office in Saskatoon where they are held in a database of records for data analysis. Different surveys were used for each type of activity. All this material was developed in such a way that ensured anonymity and with the intention of entering it in a database upon completion of the program.

3.7.3 Qualitative Data Collection

As is traditionally done in ethnographic studies, data is collected in an unstructured form at the beginning of the process and becomes more targeted closer to the end of the fieldwork.⁵² The qualitative data was collected throughout the course of this program, from members of the Advisory Committee, program coordinators, as well as breast cancer survivors who were participants at the events. A combination of data generation strategies were employed.

During events and meetings the researcher took notes in order to get a richer description of the interactions of all the individuals involved in this process. These notes provided feelings, thoughts and observations of the researcher at the time of the event that could be reviewed upon the completion of the program to assist in the analysis of results. The researcher took an involved role in the population and introduced her self as such to all participants at the events. The observational data were collected in a natural setting with formal interviews organized later on, as asking questions would not have been possible at the organized events. However, according to ethnographic methodology, a schedule should be developed to guide these observations.⁴⁷ In the current study, the program logic model was developed to guide observation and evaluation to relate participant experiences back to the success of the overall program.

Researcher observation at events was followed up with individual interviews with breast cancer survivors and Advisory Committee members to obtain more specific information about these individuals' perspectives and experiences, in a more controlled and systematic way. This technique of semi-structured interviews are commonly used in the data collection of ethnographic studies.⁴⁷ Semi-structured interviews were also conducted with members of the SBCN Advisory Committee to provide a different perspective on the perceived effectiveness of networking events and dissemination of information. Nine members of the SBCN Advisory Committee including the Program Coordinator of the SBCN, were individually invited to participate in a one-on-one interview.

Following these interviews, fifteen female breast cancer survivors were invited to participate in the project evaluation with the hope to recruit and interview approximately five of them. The SBCN compiled a list of female survivors who had attended their events and who were willing to provide feedback of their experiences with the project. These women had already released their contact information to the SBCN for the researchers in order to participate

in an evaluation interview, should they be invited. The SBCN contact consent form can be found in Appendix E. From this list, participant selection criteria for survivors are depicted in Table 3.

Table 3. Participant Selection Criteria.

| Age | Location |
|--------------------------------------|---|
| Senior survivors (over 50 years) | Rural Survivors (outside Saskatoon or Regina) |
| Young Survivors (50 years and under) | Urban Survivors (inside Saskatoon or Regina) |

It is important to note that these criteria, as well as the labels (i.e. “senior”), were defined in the program proposal developed by the SBCN. Rural participants were all those survivors not residing in the cities of Saskatoon or Regina as major cancer care clinics are located only in these cities resulting in more treatment related travel for those living elsewhere. Urban survivors were defined as those who lived in one of these cities. These age and location definitions and classifications were defined according to the program proposal submitted by the SBCN to the Public Health Agency of Canada.

Elaborating on these criteria, the program coordinator from the SBCN identified which participants, who had already consented to be contacted for the purposes of this evaluation, satisfied the above criteria. Having worked in the Saskatchewan breast cancer community for many years, the SBCN program coordinator was familiar with many of the participants of the program by name, and was able to identify fifteen individuals who met one or several of the above criteria. From this list, participants were invited to an interview one at a time, until the participants interviewed represented the key areas of criteria.

Qualitative researchers continue to collect data until they reach a point of saturation, at which point no new information is obtained. In this evaluation, once one individual was interviewed from each of the criteria categories, the saturation point was reached. Participants in the sample population needed to be interviewed, as soon after the event as possible, since memories regarding the program would fade with time.

By distributing a “Request to Contact” form, which was handed out at events by the SBCN, survivors were identified as willing to be contacted for an interview for the purpose of an

evaluation of the SBCN's program. A digital audio recording device was used to capture all interviews and was subsequently precisely transcribed. In some cases where survivors requested to review the transcript, it was e-mailed, requested amendments were made, and a transcript release form was signed and returned to the researcher and is included in Appendix F.

3.8 Ethical Considerations

Ethics approval was received on June 14th, 2010 by the Behavioural Ethics Research Board of the University of Saskatchewan and is included in Appendix G.

3.8.1 Consent to Release Contact Information

Developed by the SBCN for use with participants at their events, the consent to release contact information was distributed by the program coordinator at the same time as the evaluation surveys at all events. Consent to complete the surveys was implied when events' participants returned their surveys anonymously into designated boxes provided to this effect. Those who agreed to be potentially contacted for an interview returned the consent to release form with their contact information (see Appendix E). Survey data were made available to the researcher for the purpose of the current evaluation study.

From these completed 'consent to contact forms', participants' names potentially meeting the study criteria were selected by the program coordinator and given to the researcher. A letter of invitation was then e-mailed to fifteen survivors. . Each member of the SBCN Advisory Committee was approached separately for individual interviews by a letter of invitation, which was sent by e-mail to each member.

3.8.2 Consent for Interviews

Upon the confirmation of interest to participate in a one-time interview over the phone or in person, the researcher presented the study and went over the consent form with each participant. Individual consent forms for survivors were reviewed and the form signed prior to conducting each interview. The same procedure was followed for members of the advisory committee; Individual consent forms for key stakeholders were reviewed and the form signed prior to conducting each interview.

All participants were given the opportunity to review the interview transcript. Each participant was reminded that she had the right to withdraw, amend or omit any part of her interview and to contact the researcher at any time after the interview if she had any questions or concerns. Throughout the interview process, participants were free to withdraw their participation without any consequences. Digital audio recordings were used for each interview in order to transcribe the discussion for further analysis. The consent forms for survivors and for Advisory Committee members stating all the details regarding risks, benefits, storage of data, and participant's right, are included in Appendix H and Appendix I.

3.9 Analysis

Using a ethnographic constructivist epistemology, the current study employs a mixed methodology framework with both quantitative and qualitative analysis of data. Triangulation was used in that the quantitative and qualitative information were simultaneously collected through the course of the program.⁵⁹ The results from the interviews and observations were compared with the results collected from the surveys to develop a greater complexity of understanding.⁶⁰

3.9.1 Quantitative Analysis

A variety of surveys developed by the SBCN, were distributed at all the events run throughout the course of the program and collected by the SBCN at the end of each event. These surveys were compiled into a database for the use of the researchers in evaluating the program. This data was collected by the SBCN in 2009 and 2010 throughout the course of the program, following each event. Unfortunately, the surveys used at each event were not uniform and therefore some questions varied slightly or were asked at only certain events. Inconsistencies between surveys used at events and techniques used (i.e. types of scales, wording of the questions), as well as a lack of demographic information made the analysis more challenging. For this reason, data was arranged according to events and results could mostly be aggregated in this manner. This data reported on the frequencies of participant responses on a number of variables for the various events and were charted accordingly. As the nature of information collected at events varied according to the intended goals of the event, these charts used different

denominators based on the questions that were asked and the number of responses. All the quantitative and qualitative data were combined for the final analysis.

The events from which the surveys were collected were facilitated by the SBCN were all linked to the four components of the program: information, education, networking and support. In order to analyze the information collected from the different surveys, the questions were first reviewed to determine which were relevant to the current evaluation. Some of the questions on the forms were included to help develop future SBCN programs and were therefore not relevant in evaluating the current program.

Responses were combined according to the event from which they were collected and were input into an Excel database. Some of these data identify the category of participants attending the event while most of the questions give feedback specific to the facilitation and content of the event.

3.9.2 Qualitative Analysis

Interviews were conducted using a semi- structured interview guide, developed by the researcher in accordance with the program logic model and evaluation goals. These questions aimed to assess participant's experience within the cancer community as well as their views on the programs effectiveness in meeting their needs and the needs of the community.

After receiving the participants' consent, each interview was digitally recorded either through the phone or in-person and transcribed. Following transcription, and upon receiving consent for its use where required, transcripts were read through several times, while highlighting information relevant to the program or evaluation goals. These ideas were organized into discrete categories and quotes were compiled according to these designations. The categories were assigned by searching for commonalities among the accounts.⁶⁰

While continuing to read through the interviews, new data were organized into pre-existing categories, as well as adding and modifying other categories to accurately depict the additional information, as is done in ethnographic research.⁶⁰ In looking through the interviews for specific themes that were reflected by the program goals, several other recurring ideas became apparent to the researcher, which related to the overall experience as a member of the cultural group of the cancer community. Through triangulating these ideas between the researcher's notes, the discussion with the supervisor and the body of research on survivorship,

they were organized into additional themes.^{47,50}

According to the constructivist epistemology, these categories were analyzed as unique constructs of each survivor or Advisory Committee members. Overall, these themes aligned with key program goals areas and by organizing them in this way it allowed the researcher to infer meaning from these results. These texts were analyzed in order to uncover varying perspectives on the impact of the SBCN's program and to understand how each individual's constructed experience was related to the effectiveness of the overall program.

4. RESULTS

In order to evaluate the program to determine if the two goals were met, the data have been cumulatively reported with quantitative and qualitative data organized according to the program logic model and evaluation goals. The first and second sections outline the participants of the event and interviews as well as the attendance at events. This illustrates the number of events that were carried out, and the demographics of those in attendance. The third section reports data pertaining to the four program components established by the SBCN, which support the assessment of whether the overarching goals of the program were met. The fourth section presents data related to the facilitation of the program and the role of the SBCN Program Coordinator in relation to the manner in which the program was carried out and to the intended effect among participants. The fifth section highlights regional influences in meeting the needs of survivors in Saskatchewan, whereas the sixth section reviews more specific experiences shared by interview participants surrounding survivorship, a strong theme in the literature and a guiding framework for many qualitative studies on surviving breast cancer. Finally, the seventh section of this chapter supports the need for broadening the scope of the Network to encompass all cancers, a focus that was directing the work of the Advisory Committee throughout the current program.

4.1 Interview Participants

Participants invited for interviews included members of the Advisory Committee and selected breast cancer survivors. Twelve interviews were completed seven of which were Advisory Committee members. Of these members, three of them identified themselves as being breast cancer survivors themselves. Five breast cancer survivors who were not on the Advisory Committee, who had attended at least one of the SBCN's events, were also interviewed. These survivors were invited based on predetermined criteria and represented characteristics deemed relevant for the program: different age groups (young and older), residence (rural and urban). With the Advisory Committee members and the survivors who had attended events, eight participants were breast cancer survivors.

All the members of the Advisory Committee but two, agreed to be interviewed including the two program facilitators: one from the Canadian Cancer Society and the other, the Program

Coordinator from the Saskatchewan Breast Cancer Network, who was a breast cancer survivor as well. A representative from each of the following groups was also on the Committee: Les & Irene Dubé Centre of Care Saskatoon (Breast Health Centre), HOPE Cancer Help Centre, and Saskatoon Health Region and was interviewed. The two breast cancer representatives on the Advisory Committee also agreed to be interviewed. One of these women was diagnosed when she was young and lived in an urban community. The second woman was a senior when she was diagnosed and was living in a rural community. The number of events that the Advisory Committee members attended ranged from one to all events.

Two of the breast cancer survivors interviewed had been diagnosed when they were young (37 and 31 years old) and lived in rural communities. A third woman who was also young and live in a rural community identified herself as Aboriginal, diagnosed at 41. The other two women interviewed were both older (54 and 70 years old) when they were diagnosed; one lived in a rural community and the other lived in an urban community. These survivors, who were not on the Advisory Committee, each attended one event.

4.2 Participants of Events and Activities

The overall program *A Thinking, Learning and Caring Collaboration: Promoting a Healthy Lifestyle* facilitated by the SBCN and informed by the Advisory Committee was collaboratively planned, implemented and disseminated. “This project involved representation and participation of senior, young, rural and Aboriginal breast cancer survivors, network partners, health region personnel and small urban communities” and reached out to approximately 582 participants in sixteen independent communities.¹¹

The Saskatchewan Breast Cancer Network had identified attendance of the general public, key stakeholder, Advisory Committee members and survivors at events as an indicator of its success and therefore it was essential to collect this information from each event. Once the programs were carried out in several communities, it became clear that there was difficulty in always attracting a high attendance.

Sometimes we didn't know whether the attendance was going to be that good, but the people that were there really enjoyed it and really felt that it was worthwhile. So then, that made us realize that it was worthwhile doing too. - Advisory Committee Member

It's hard to judge things on attendance, because you go into Yorkton - well you hopefully you don't have a hundred people with breast cancer in Yorkton. You maybe have three. And so if two come then that's a success. – Advisory Committee Member

Advisory Committee members speculated that perhaps the numbers in attendance were not as important as originally believed if the needs of survivors were being met. In addition to the total number of participants reported below, data pertaining to the distance traveled to get to the event as well as the respondents personal experience with cancer (i.e. survivor, family of survivor, health care provider) enrich the demographic data and paint a clearer picture of who the program reached. This information is organized according to event.

4.2.1 Thinking Learning Caring: Survivor Think Tank

The first survivor think tank was held on September 18, 2009 in Saskatoon. The topic of this think tank was “Life After Breast Cancer: Living a Healthy Lifestyle.” This one-day workshop brought together twenty-three women who represented young, senior, urban and rural survivors. Although it was a small group, there was diverse provincial representation as can be seen in Figure 4. It is important to note that while there were twenty-three women in attendance, only twelve surveys were completed. One of these twelve survey respondents chose not to answer this question and is not graphically depicted.

At the Survivor Think Tank, the largest group of participants only traveled between 10 and 20 kilometers to attend this event (46% of respondents), but was closely followed by those who came to Saskatoon from over forty kilometers (36% of respondents). This highlights the presence of both urban and rural survivors and can be seen in Figure 4 below.

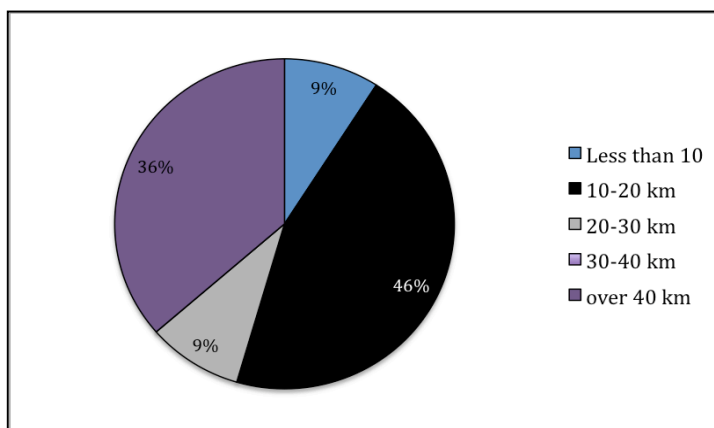


Figure 4 Distance Traveled by Survivors to Survivor Think Tank (n=11).

4.2.2 Aboriginal Women and Cancer: Survivor Think Tank

The second Think Tank, held March 11, 2010, brought together thirteen Aboriginal breast cancer survivors. The student researcher was not present at this event, and information about this event was gathered by the SBCN through observation and participant self-report surveys, which were then shared with the researchers. The majority of these women were either breast cancer survivors themselves, or family members and friends of a cancer survivor pictured below in Figure 5. Through participating in this five-hour workshop these women provided input regarding their personal needs and concerns about adopting a healthy lifestyle. A “Talking Circle” format was used to allow the participants to share their stories prior to discussing health education and information.

At the end of the workshop, which was co-chaired by two Aboriginal breast cancer survivors, participants were invited to fill out the *Making Healthy Life Choices* questionnaire, similar to the one that was used in other events. Seven of the thirteen participants chose to complete and submit this questionnaire.

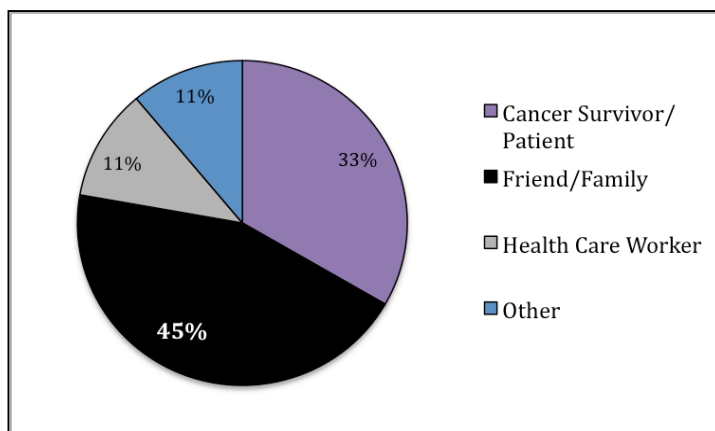


Figure 5 Participant's Experience with Cancer from Aboriginal Survivor Think Tank (n=9).

4.2.3 Telehealth Education Session

On October 1, 2009 a Telehealth session was held on the topic of *Natural Health Products and Breast Cancer*. Presented by a pharmacist with the support of the Saskatoon Cancer Centre and the Saskatchewan Cancer Agency, the session was filmed at the Royal University Hospital in Saskatoon. Eleven communities accessed this presentation remotely, with an overall attendance of 96 participants. The number of participants varied widely between each

of the sites. Surveys were sent to participating sites in advance, were completed and returned to the SBCN after the presentation. The surveys had a very high completion rate with 90 returned via mail to the SBCN office in Saskatoon. All follow-up questions from the event, beyond the scope of the presentation, were directed to the Canadian Cancer Society cancer information service toll free number.

4.2.4 Connecting the Breast Cancer Community

The Connecting the Breast Cancer Community event was held in Saskatoon on December 4, 2009 and then again in Regina on March 12, 2010. A total of 167 people attended these two events cumulatively and 93 surveys were collected from these two events (n=93). An additional survey called *Making Healthy Life Choices* was collected only from the Regina event, and therefore cannot be used as part of the cumulative data. This survey included additional questions that were not asked in Saskatoon, but are relevant to this evaluation. The questions asked only in Regina include the 49 survey respondents. When the same questions were asked in both Saskatoon and Regina, the results were combined, as these events were very similar.

In Regina, the largest groups of respondents were breast cancer survivors (48.3%), followed by health care workers (28.3%), and then family members or friends of someone diagnosed with breast cancer (21.7%). Each person could choose more than one category for their relationship with cancer and so the total responses below in Figure 6 are greater than the total number of survey respondents (n=49).

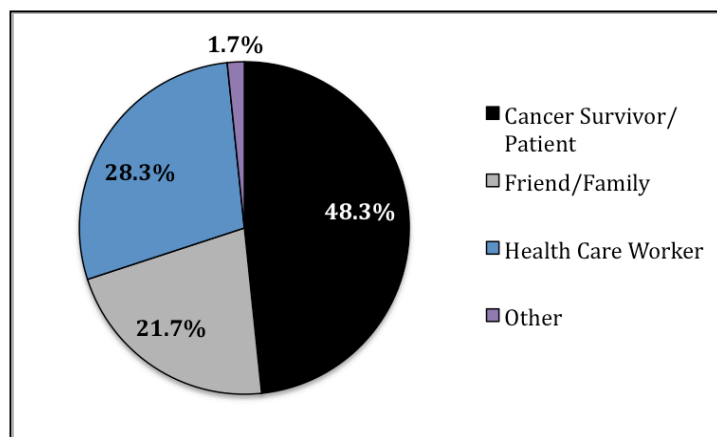


Figure 6 Participant's Experience with Cancer from Connecting the Breast Cancer Community (Regina Only, n=60).

4.2.5 Making Healthy Life Choices

The event called *Nutrition and Cancer: Reducing Risk of Cancer and Recurrence* was held in Rosetown, Saskatoon, Prince Albert and North Battleford. A similar event called *Health Living and Cancer* was held in Estevan and Weyburn. Each of these events included a presentation and the *Making Healthy Life Choices* questionnaire was collected from all participants who wished to respond.

According to the final report from SBCN, various events took place throughout March 2010, and are summarized as follows:

(1) On March 5, 2010 in North Battleford, 24 participants attended the event and of these, 21 people completed a questionnaire.

(2) The next event held was in Prince Albert on March 16th, 2010 in collaboration with their Canadian Cancer Society Cansurmount support group. Seventy-two participants came to this event and included survivors, public, health region dietician and health providers from surrounding communities.¹¹ From this event, 60 completed questionnaires were collected.

(3) On March 19, 2010 in collaboration with the local dragon boat team *Busting with Energy* this event was then held in Saskatoon. The SBCN invited the entire Dragon Boat membership and their connections, Survivor Think Tank participants, Peer Support program of Canadian Cancer Society as well as sending a general e-mail announcement through the Network's directory. This event was also held in the evening to accommodate younger breast cancer survivors unable to attend daytime events, however the registration for this event was still very low with eight people in attendance and six questionnaires collected.

(4) On March 29, 2010 in Rosetown the event was held in collaboration with the local cancer support group. There were 38 participants in attendance, 33 of whom completed a survey and included: survivors, public, and community leaders.

(5) The events held in Weyburn and Estevan on March 23, 2010 were promoted extensively by the following groups: the local unit Canadian Cancer Society, the health region, paid advertising, radio promotion, posted posters and support from the Canadian Cancer Society local *Relay For Life* volunteers. Participation of 41 included survivors, health region representatives and public. Displays included SBCN resources from partners, Canadian Cancer Society, Live Well with Chronic Conditions and Sun Country Health Region. Specifically, there

were 19 people who attended the event in Estevan and ten who submitted questionnaires. In Weyburn, 21 people attended the event and ten submitted questionnaires.

For the purposes of this evaluation, the results from each of the Making Healthy Life Choices events have been combined in the tables below to portray the overall feedback from this series of presentations. Figure 7 shows the participant's experience with cancer, meaning how they identify their relationship with the disease. An additional four people who submitted surveys did not complete this question and were therefore excluded from the total number of responses.

Overall these events drew a larger proportion of people who identified with being a family member or friend of someone diagnosed with cancer, than any other group. It is important to know that each respondent was able to choose more than one group, for example a health care worker who was also a cancer survivor. For this reason the number of total responses (n= 175) is more than the total number of surveys completed (n=140).

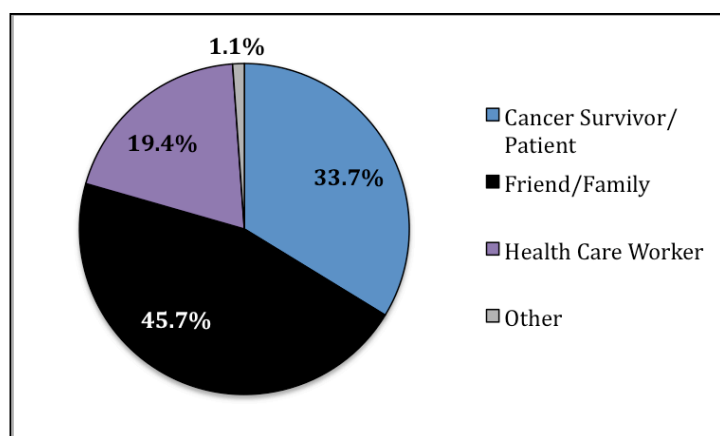


Figure 7 Participant's Experience with Cancer from Making Healthy Life Choices Events (n=175).

4.2.6 Events and Activities Not Realized

The first goal of the evaluation was to determine to what extent the program proceeded as proposed. Therefore it is essential to highlight the events were not carried out as originally planned and determine the impact of these missed opportunities on the overall program.

In the fall of 2009, shortly after the program began, there was an outbreak of the H1N1 flu of pandemic proportion, with many reported cases in Saskatchewan. Because of the

emergency response required to control the virus and treat those infected, Health Regions throughout the province were forced to focus their resources to the control of H1N1. This situation led to the inability to network and collaborate between the SBCN and the Health Regions, or to develop a partnership surrounding any of the intended events.

Not only were Health Regions preoccupied by the outbreak, but breast cancer survivors and the general public were reluctant to participate in any activity that could have put them at risk of contracting H1N1. This would have included public gatherings such as the events planned by the SBCN.

There was no way the SBCN could have anticipated or planned in advance for such an occurrence, but the event that H1N1 had on the entire project was significant. This included intensive application of resources that were not anticipated or planned for this project such as additional time and energy beyond the proposed work plans. These efforts were carried out by the SBCN program coordinators in order to reschedule and revise planned activities in order to achieve the goals set out by the program.¹¹

The Education Sub-Committee. While this working group was established as a means to ensure scope and quality of activities and products respecting the needs of target population and goals of project, it did not effectively come together as per the intentions of the SBCN's program.

Community Think Tanks. The SBCN developed two Think Tanks in order to identify the "information and education needs, gaps and themes that impact promoting a healthy lifestyle in Saskatchewan communities."¹¹ In order for these events successful meet their intended goals, the SBCN expected the committed collaboration from the Health Regions, especially since the information collected would benefit Health Regions in future planning of events.¹¹ However, the SBCN perceived "weak collaboration" on the part of the Health Regions and were recognized in the following areas: (1) limited cooperation in facilitating events which would hinder success; (2) risk of damaging further relationship building by moving ahead with the planned activities; and (3) limited confidence in the Health Regions use of the information collected from events.¹¹

Based on these obstacles the SBCN Advisory Committee recommended that using another means by which to collect information with a wider scope, beyond the originally planned

focus on two communities. Upon consultation with the Health Regions regarding this new direction, there was a clear preference on their part to collaborate on educational events instead of information gathering such as the Think Tank. This was because the Health Regions felt that the Think Tank process would possibly create too much responsibility and expectation on their part.¹¹ Moving ahead, the SBCN developed the *Making Healthy Lifestyle Choices Questionnaire* to replace the originally planned Think Tank in order to continue working towards achieving program objective.

4.3 Program Components

Data from the interviews and self-report surveys were first organized according to which of the four main components of the program they fell under. In the program logic model these four components are education, networking, information and support. This program depiction, which was based on the grant proposal developed by the Saskatchewan Breast Cancer Network, illustrates each outcome and indicator as a function of all these main pillars combined. These four components, and the events developed to support them, cumulatively contribute to the realization of three overall program objectives.

4.3.1 Education

The first component of the program was education, which referred to knowledge gained by the survivor or stakeholder. It was evident that there was a thirst for education among event participants, who may not have had many other opportunities to learn about breast cancer despite having gone through it. At Connecting the Breast Cancer Community events there was much learning with almost all respondents citing at least some knowledge was gained as is depicted in Figure 8. Though not depicted, this scale ranged from 1 (not at all) to 5 (a great deal).

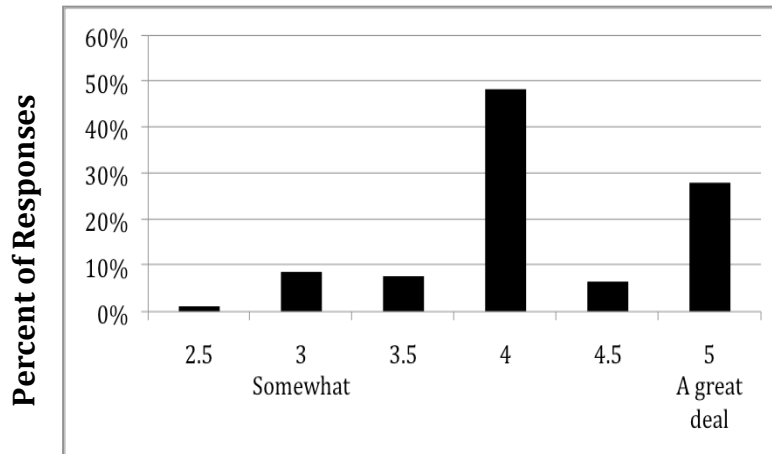


Figure 8 Amount of Knowledge Gained at Connecting the Breast Cancer Community (Saskatoon and Regina, n= 93).

Respondents commented that visual information was powerful, and additional resources such as pamphlets and information books were helpful in the learning process. However, people interviewed did report that this and other events throughout the program just re-iterated the knowledge they already possessed.

I think education was a primary focus and need of the survivors. They needed that education when it was right for them, not when our system said it was right to be given the education and the support. – Advisory Committee Member

There were many things I didn't know, and still a lot that I don't know. There was a lot that came out of that, almost overwhelming, there was so much. But it was very good. – Survivor (senior, urban)

I think that depending on who it is that your talking to, the event should be coordinated to the people that are there. Most of the people that were at this particular event and for this particular type of event, most of the information that they taught us we already knew. – Survivor (young, rural)

At Connecting the Breast Cancer Community, despite the high rate of knowledge gained, some respondents found some presentations to be repetitive of information they had already acquired. One participant commented that she “felt some of the information would be more helpful [but since it was] more generalized, which would be okay for others; for myself more in depth was necessary.” For example, one participant was specifically “looking for information on

natural kinds of healing” or “more information on breast cancer itself.” However, the variety of topics facilitated a broad range of information gathering and the professionals giving presentations were well received. Even when participants were already aware of many of the topics, the event was “still a great renewal of information.”

One specific type of education was pertaining to how survivors could lead a healthy lifestyle, which was a main focus of the program. A new addition to the SBCN’s programs, healthy lifestyles, was strategically chosen to increase interest in learning about breast cancer.

[It] was a way of targeting a different population, but at the same time, including that breast cancer information. Especially now because it’s presumed that a lot of people aren’t going to come out for just breast cancer information. So they came out because of healthy lifestyle, but at the same time through the programs of this last project, they heard that there is information available. – Advisory Committee, Survivor

In my opinion I believe that our health care system should be called sick care system, because it’s based on treatment after illness, instead of prevention before you get ill... [the SBCN is] getting the information out there that this is what you need to do to keep your good health and this is why. – Survivor (young, rural)

At the Thinking Learning Caring Think Tank, survivors spent much of the day on one particular activity which involved using Post-it™ notes to identify barriers survivors faced in leading a healthy lifestyle, though a more comprehensive agenda was initially planned. These Post-it™ notes were placed in groups depending on whether the survivors believed it was a challenge faced primarily or solely by rural, urban, young, or old women. An additional category was used for challenges faced equally by all the groups. These groupings of post-it notes were collected after the event and common themes were identified.¹¹ These themes are summarized in the Think Tank Recommendation Documents in Appendix C and Appendix D.

Though barriers exist in adopting a healthy lifestyle, Figure 9 depicts the impact of the Making Healthy Life Choices events on participants’ efforts to make healthy decisions, which took place in Rosetown, Weyburn, Prince Albert, Saskatoon, North Battleford, and Estevan. The majority of respondents stated that the event had at least somewhat of an impact on these efforts (93%). An additional 17 individuals who submitted a survey, did not answer this question.

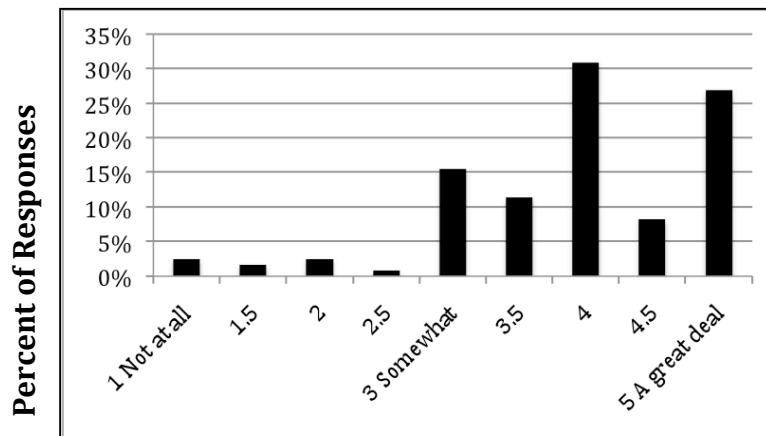


Figure 9 Event's Impact on Efforts to Adopt a Healthy Lifestyle from Making Healthy Life Choices Events (n=123).

The majority of respondents who completed the question about the extent of learning to support making healthy life choices found that they learned at least something from the event (91%) as illustrated in Figure 10 below. Twelve people did not respond to this question. Not included in the figures, participants' reported their perceptions of whether they would have been able to access healthy lifestyle information without having attended the event. When all the locations are combined, the largest group of respondents also cited that they would have been able to access this information, even if they had not come to the event (42%). However, a similar percentage of respondents were not sure if they would have been able to find the information offered through the event elsewhere (39%).

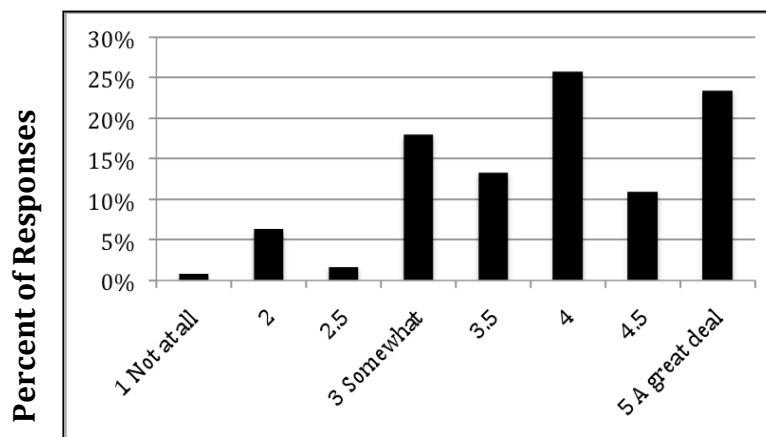


Figure 10 Extent of Learning at Making Healthy Life Choices Events (n=128).

From this event series that focused on healthy lifestyles for breast cancer survivors, it was clear that both survivors and stakeholder learned about not only healthy lifestyle choices, but also about breast cancer in general.

Lots of good explanation why they recommend the different food types and the exercise and everything that goes with it. - Survivor (rural, senior)

That is amazing how all of a sudden at a workshop someone will come up and say: 'Well I just came with a friend, and I thought I was only going to come and learn about healthy lifestyle, but my aunt has breast cancer and for the first time I understand it' ... It helps even beyond the breast cancer. It helps in cancer general; of giving that message to our public of Saskatchewan that there is information, there is education, there is support.
– Advisory Committee Member, Survivor

The intention was for the learning's to go further than just the person who attended the actual event. This is especially true of women who were able to travel from rural areas to attend the larger conferences in Regina and Saskatoon. Each woman who attended from a small community represented many more women who weren't able to make it to those events, but who required the education.

We always hoped that if the breast cancer survivor got that knowledge that they would almost be like an ambassador and take that back and share it with other people. And that would also help us increase awareness. – Advisory Committee Member

Breast cancer survivors benefited not only directly from their attendance, but indirectly based on the education of the stakeholders and Advisory Committee. With their new knowledge, service providers became better equipped to tailor their services and policy to meet the needs of the survivors. For the stakeholders attending events gave them the opportunity to learn from the survivors in ways that they had not yet had an opportunity.

As we're developing or hoping to expand our program here at the Breast Centre, [the survivors are] who we have to listen to. They know what they need - we don't. We shouldn't be telling them what they need. – Advisory Committee Member

The Survivor Think Tank gave me a whole new look at things to, to sort of hear their side of the story and what they're looking for. So it gave me a greater appreciation for their needs. – Advisory Committee Member

It's absolutely fascinating to hear it right from the survivors and it really changed how we [regionally] looked at programming... how we looked at programming and how we looked at tools and bringing together. – Advisory Committee Member

Being very green to the breast care community and learning what's out there I felt like a sponge - like I was getting lots. It certainly helped with the vision of what we need to do here. – Advisory Committee Member

With my input as a survivor it was easier when I talked to young women to hear what their struggles were, I could bring it back to the table and I could say okay, this seems to be important... And from that we were able to determine what the high needs were. And then from there we took the plan and decided okay, this is what we're going to do. –Advisory Committee, Survivor

4.3.2 Networking

The second component of the program was to sustain networks and collaborating at the Advisory Committee level, the provincial level and at the national level for survivors, family members, communities and stakeholders. Although networking has been the focus of other programs put on by the SBCN, it continues to be an important component of their work.

I think you can never assume that collaboration is working, is just established and is going to keep on. – Advisory Committee Member, Survivor

There's a lot that out there in this province but we have ... difficulty making those connections. So, I feel that the Network really helped provide [that]; whether it was an opportunity to meet people and network. – Advisory Committee Member

Advisory Committee. The networking began at the Advisory Committee level where stakeholders working in cancer across the province were brought together to advise of the SBCN's program. These members of the Advisory Committee had been approached by the SBCN Program Coordinator to be on the Advisory Committee because of what they would be able to contribute to the facilitation of the program. They had all met her through their work in the Saskatchewan cancer community, either as service providers or as survivors who had

attended at least one event. The Advisory Committee always included one woman having the lived experience who represented voice of breast cancer survivors.

The goal was to have an Advisory Board that was consisting of the partners that were organizations [and] agencies that were involved in Saskatchewan that were contributing to the women of Saskatchewan and the public of Saskatchewan who were affected by breast cancer or concerned about breast cancer...So it was the whole continuum of breast cancer and that was the goal right at the beginning and always to have the breast cancer survivor having a major role, or being involved in any aspect of the program delivery. – Advisory Committee Member, Survivor

There were many positive feeling about being an important member of this committee and contributing to the overall goals of the SBCN.

I came on the committee because [the SBCN Program Coordinator] had asked me to help them out; they were missing somebody there and I've got a history of breast cancer. I do have a positive attitude maybe that would help a little bit in other directions too. –Advisory Committee Member, Survivor

After our events, just having that conversation at Advisory Committee meetings about the events that took place and, and how things went and that helped. And of course, chatting back and forth with [the program coordinator] after. You know, what worked what didn't work type thing. – Advisory Committee Member

However, there were some concerns regarding support of the work of the Advisory Committee that arose. Though this does not take away from the good intentions of the committee members, the commitment of individuals may not have been adequate.

When people come to a Network, when you're there it's good but then everybody leaves and goes back to their own job. So it's hard to sort of just have everybody committed to doing something all the time. But there was definitely some input from some of the people on the committee that helped steer us as to what we wanted to do. – Advisory Committee Member

[The program coordinator] really carried the Network. And not everybody pulled their full weight. There are probably other reasons; there are other priorities where they work and whatnot. But it's hard to carry on when you don't have that full support either. – Advisory Committee Member

National Connections. Beyond the provincial connections, the SBCN attempted to increase the scope of the breast cancer community to include learning's and support from across the province. This effort worked towards aligning key messages across the country and learning from the work done in other communities and well as sharing successes.

In developing an activity within the Network, I could look at what other areas of Canada and say, 'have you done this activity? What, what were your lessons learned?' and then adapt them to Saskatchewan... We always had access to what was going on nationally. – Advisory Committee Member, Survivor

Getting past the individuals we're dealing with and I think that would be a good strategy if the network continues is to say, 'okay, it's time to present to you know, um, the board of the Cancer Agency or the CEO of the Cancer Agency... to the board of the Canadian Cancer Society to [Breast Cancer Action Saskatchewan]. – Advisory Committee Member

What Saskatchewan was doing was good in supplying our key learnings and sharing with national organizations that were wanting to do the same thing. And also learning from them. – Advisory Committee Member, Survivor

Connecting Survivors and Stakeholders. Many survivors from the various events and activities felt that these events successfully enabled their networking intentions. Connecting the Breast Cancer Community participants from both Saskatoon and Regina found the events to be a “great networking opportunity.” One respondent said that it was good to come to an event like this with other survivors as “we are not alone – more information [is gained] from fellow survivors than books.”

The key word is communal. If you were going to look at a survivor ...and [she] has been sitting with a gown on and having a small amount of time to access. And it's doctor this and nurse that. And now she's in the room [at an event] and she could be sitting and having lunch with this doctor or with this nurse and they're sharing every day things. So it becomes community, not they or them. – Advisory Committee Member, Survivor

The vast majority of respondents cited that they had made contacts at the event (98%) as can be seen in Figure 11, with seven people not responding to this question. Many people commented that they enjoyed the opportunity to connect with other survivors, *Busting With Energy* dragon boat team members and presenters. One responded said that “talking to other

survivors was extremely helpful – a lot of good information was exchanged at [the] table” which was made up of six survivors. Another participant not only benefited herself from making contacts but “appreciate[d] the chance to be able to take the contact information back to [her] support group in [her town].”

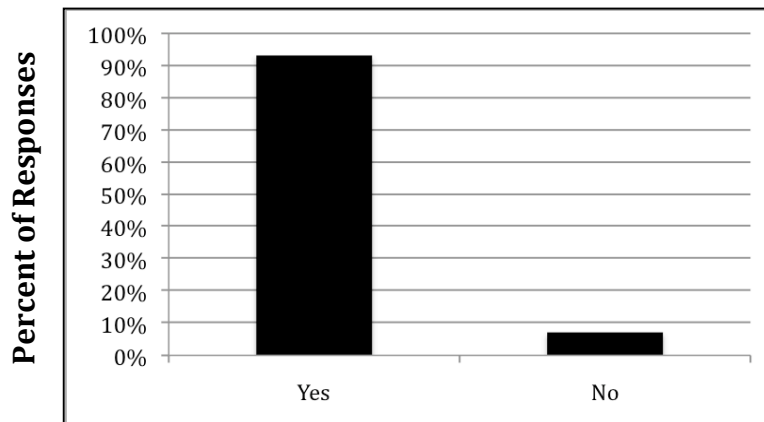


Figure 11 Making Contacts at the Connecting the Breast Cancer Community Event (Saskatoon and Regina, n= 93).

At the Thinking Learning Caring Survivor Think Tank, survivors were asked their main reason for attending, with much consistency among participants’ responses. Survey respondents were able to select more than one item that they believed were their main reasons for attending the event, and therefore the results are displayed as percent of responses (Figure 12).

Participating in the discussion of breast cancer survivors living a healthy lifestyle was the most widely chosen response, 45.5% of all responses. Next linking with other survivors (27.3%) was reported, followed by having an opportunity to share experiences (18.2%) and other (9%). These additional reasons for attending the event as provided in participants’ comments, was that this event gave them an opportunity to “help other current and future survivors to live well” as well as keep up-to-date on “the latest things that are going on in Breast Cancer research.”

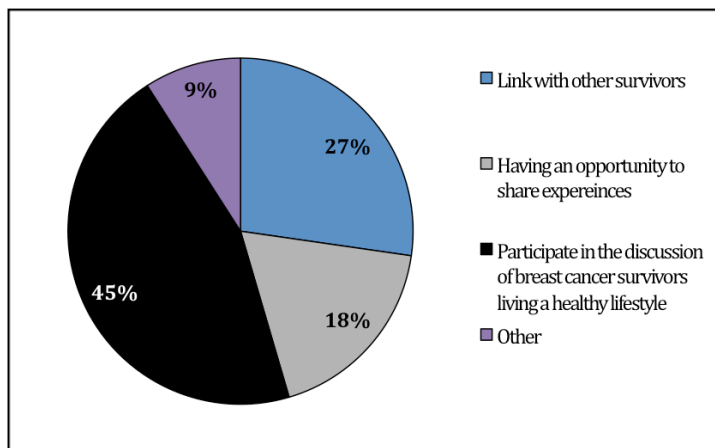


Figure 12 Main Reason for Attending Thinking Learning Caring Survivor Think Tank (n= 22).

Similarly, at the Connecting the Breast Cancer Community events in both Saskatoon and Regina event, participants were asked to check off the main reason they attended the Connecting the Breast Cancer Community event. Many respondents chose more than one reason, but these responses have been depicted proportionately and are illustrated in Figure 13. Of all the choices, the majority of respondents chose “learn about services, resources and organization connected to breast cancer” as at least one of their reasons (approximately 42.4% of responses).

[In] being able to connect [breast cancer patients] with what’s out there...we would be connecting with the Cancer Agency and we would be connecting with the Canadian Cancer Society and with HOPE and bringing speakers in, and you know, what’s after this? What’s after cancer? I think we can do it. – Advisory Committee Member

Linking with other survivors was commonly chosen (approximately 23.3%) followed closely by opportunities for networking (approximately 20.3%). Finally, providing information on the individual’s organization or services, for participants who were not survivors but community stakeholders were 11.6% of responses. A small number of responses, 2.4% noted other reasons for attending which included wanting “to know more about the breast cancer community” for someone who was new to town, to be “current with the information I share” and “to a means to learn and also to send messages back to the healthcare providers regarding services.”

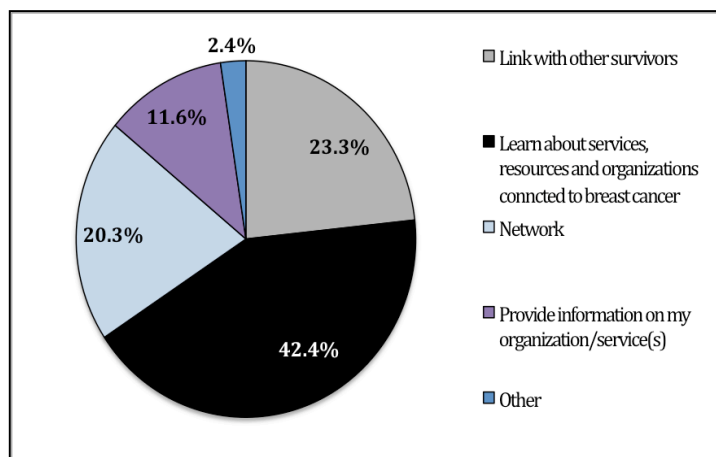


Figure 13 Main Reason for Attending Connecting the Breast Cancer Community (n= 172).

Advisory Committee members were in a unique position as they often dealt with the community of breast cancer survivors and with service providers. By making additional connections with both of these groups, they were able to become the intermediaries to match the needs of the survivors with the available services.

If [event participants] have support groups ... when I get a newly diagnosed person, I'm able to refer them to the different support group and everything. – Advisory Committee Member

I now have a wealth of people to call upon if I need to –for myself or for anybody else that asks for my help. – Advisory Committee Member, Survivor

The ability of the Advisory Committee members to match survivors with services would not have been possible without the networking between stakeholders. Through their attendance at events they learned about the work being done throughout the province as were able to connect with individuals working in the field.

What was important to me was to first of all get a better understanding of all of the different advocacy groups and interested individuals in breast cancer and how they work together. – Advisory Committee Member

I think that [the SBCN] were very, very instrumental in pointing us in the direction of other agencies because we can't be all things to all people. But if we can find other people out there who are willing to help us and do a partnership then, terrific.

– Advisory Committee Member

I think the big thing is that it, it brings us all to the same table and that we can all agree on, that this is what we want to have for consistent messaging, that we don't want any duplication of certain services. ... it's good to work with others that can share in the workload. – Advisory Committee Member

There are some people that just don't get it. There are some people that don't want to play ball that I think should be playing ball and that makes me mad. I think that there is some people out there just for themselves and what they can take and turn it around so that they can produce it as their own... You'll never get away with that, for any committee I've ever sat on there's always some of that; people with their own agendas. – Advisory Committee Member, Survivor

Saskatchewan North-South Connections. In Saskatchewan breast cancer services tend to be centered in the two major cities, Saskatoon and Regina. Regina usually serves the southern half of the province and Saskatoon the northern half. For this reason many of the stakeholder were unaware of the work being done in the other half of the province and these events gave them an opportunity to network with people doing similar work in Saskatchewan.

I connected with people from other organizations and other facilities and came back and was able to pass on business cards and say 'Oh, they're doing this really neat thing in Regina'. Part of the reason I went to Regina instead of Saskatoon was to try to get that.

– Advisory Committee Member

I really enjoyed going down [to Regina] in March, meeting with people from the southern half of the province, because we have a tendency to sort of focus on what's happening in Saskatoon. – Advisory Committee Member

Women came from all over the province and had an opportunity to meet with other women from all over the province. – Advisory Committee Member

I've had a lot of referrals that have started coming from the south of the province, which was just incredible. We never had that before. ... So it broadened our scope so we were able to actually do what, what we're supposed to be doing. – Advisory Committee Member

4.3.3 Information

The component of information was incorporated into all the events to ensure this need was being met. As made evident in the data collected the specific timing, availability and content of the information were key areas of importance in achieving this goal for survivors.

Timing of Information. When women are going through their treatment, they may not feel ready to take in all the information that they may require for the remainder of their journey with breast cancer.

[The] information I got from the cancer clinic... it's almost overwhelming that the reading material and all the information you get. You are not in the state of mind to be reading all that material – Survivor (rural, senior)

I think it's very imperative that when anyone goes in and sees their specialist for the first time that they take somebody with them. Your overwhelmed as it is and you miss a lot of information... By the time you get home I don't think you remember how the entire day went. – Survivor (young, rural)

However, once they are in a state of mind to seek out information by coming to a Network event, the Program Coordinator ensured that at that point they would have access to all the information they required by continuing to be a point of contact for participants, even after the event was over.

A key thing is always making sure that there's access to resources after any activity, so that there was follow-up... There was a way of making sure through their handouts or the actual oral presentation of increasing understanding, decreasing misunderstanding. – Advisory Committee Member, Survivor

Availability of Information. Although many of the participants of this study had tried to find breast cancer information for themselves, they found the experience overwhelming and frustrating. Although the information may be available for those who seek it out, the security of knowing the quality and validity of the information shared by the Network may provide comfort to some survivors.

It was amazing the misinformation that [event participants] had as well as the lack of information. And so that for me was really rewarding because it was nice... to walk away thinking that these women get it now. They are armed with as much as they could process and that will carry to the people that they talk to and it just widens that circle. - Advisory Committee Member, Survivor

To determine the educational impact of the Making Healthy Life Choices events, the extent of learning was assessed as well as whether this learning could have otherwise been achieved included in Figure 14 below. The results of accessibility of information are included for rural respondents, urban respondents and the total combined response. In the urban centres, which in these programs included Prince Albert and Saskatoon, 47% of respondents said they could have otherwise found the information.

I don't think there's any lack of information if people want to find something. It's not hard to find. I think the Network wants to, like bring it forward so people don't have to look so hard. – Advisory Committee Member, Survivor

Interestingly, 40% of respondents said they were unsure of whether they could have accessed this information otherwise. For the rural centres, which in this study include Rosetown, Estevan, Weyburn and North Battleford, 38% of respondents said they could have found the information on their own, and 39% of respondents were not sure.

In the urban centres, only 12% of respondents said they would not have otherwise been able to access the information if not for their attendance at the event. This is the greatest difference in the responses between the two locations as 24% of rural respondents felt like they needed to have attended the event to access the information.

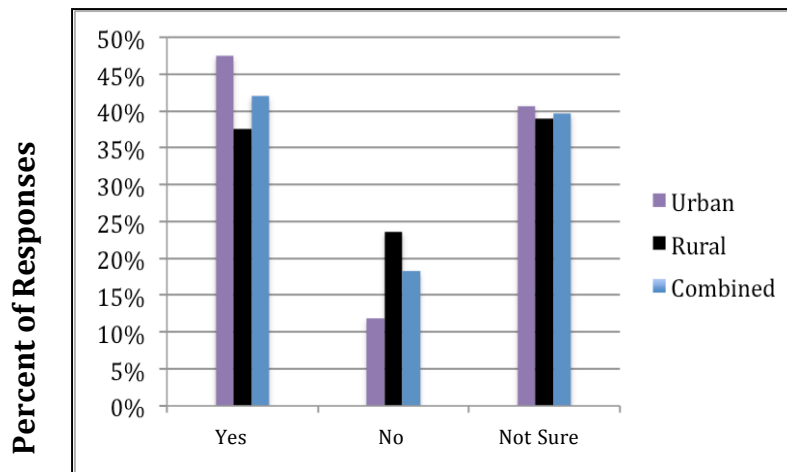


Figure 14 Accessibility of Information Without Making Healthy Life Choices Events (n=140).

Towards the SBCN's program objective of increasing breast cancer survivor's awareness and access to information promoting a healthy lifestyle, the Survivor Think Tank Recommendation Document was developed. Through information collected at the Survivor Think Tank and the Aboriginal Women and Cancer Think Tank, it was possible to compile the *Survivor Think Tank Recommendation Document* for each of these groups (Appendix C and Appendix D). A summary of the main recommendations made by the survivors includes: (1) Greater emphasis on breast cancer after treatment rehabilitation through developing programs based on initiatives such cardiac rehabilitation and the *Live Well with Chronic Conditions* program; (2) Move to categorize those living as breast cancer survivors as those living with a chronic condition; and (3) *Healing Leads to a Healthy Lifestyle* document.

There's kind of information scattered all over the place and I guess for me it was [that] I don't want to have to go to five or six different places to find the information that I want. It's nice to have a central location. And so for me my journey was very frustrating.
- Advisory Committee Member, Survivor

I used to find information on the Internet and I don't do that anymore because you never know if it's the right information. I don't do that anymore. It just scares you...most of the time it's nothing. – Survivor (rural, young)

Content of Information. At the Connecting the Breast Cancer Community Events, the focus was on helping clarify the relationship of local, provincial and national breast cancer organizations and service providers for both stakeholders and survivors. This would better equip patients and survivors to seek out the services they require from the providers that would best suit their needs. Navigating through the system of breast cancer services in Saskatchewan and nationally was seen as a point of contention for many breast cancer survivors.

There's so many different organizations and groups and stuff out there that it would be a lot easier if they could communicate more... There's just lots of different groups out there that, you don't know who you should be calling or talking to. – Survivor (young, rural)

I think people become confused because there are so many different types of breast cancer societies out there... I think people are totally confused. - Survivor (rural, senior)

Although there was a benefit from women who had attended these particular events, not all women interviewed had attended such an event, and still found navigating the system to be challenging. The many different service providers available in the province surprised even members of the Advisory Committee.

I didn't know that [the different services] were there. So it must be confusing for cancer patients - I work in that field and I was just absolutely boggled at the resources that are out there. – Advisory Committee Member

Meeting individuals [at Connecting the Breast Cancer Community] and making those connections were important. Just to be aware of the groups that are available if we see families or patients who have that kind of need. – Advisory Committee Member

As the events progressed, the SBCN decided to develop the *Making Healthy Life Choices Questionnaire* to collect information pertain to the information needs of survivors for adopting healthy lifestyles. At Connecting the Breast Cancer Community in Regina, the Aboriginal Women Survivor Think Tank and the various Healthy Life Choices events, this survey was collected and healthy life choices questions were asked. Each respondent checked off the information they believe they need to support them in adopting a healthy lifestyle from a list. Respondents were able to choose as many information needs they felt applied as well as add any additional areas they feel were not included in the given categories. At Connecting the Breast

Cancer Community, the most commonly cited information need for adopting a healthy lifestyle as depicted in Figure 15 was physical activity (23%) closely followed by healthy eating (22%) and reducing and managing stress (18%). The participant's environment, chronic diseases and reducing the risk for cancer or recurrence were cited 38% of the time. An additional six people did not respond to this survey question.

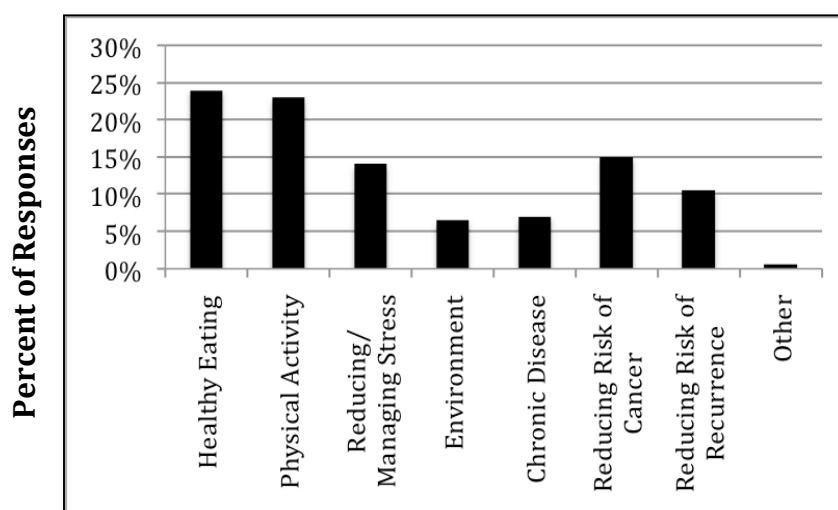


Figure 15 Information Needs for Supporting Healthy Lifestyles: Connecting the Breast Cancer Community (Regina Only, n= 156).

Healthy lifestyle questions were again asked at the Making Healthy Life Choices events and are depicted cumulatively in Figure 16. Most respondents did in fact choose more than a single information need and therefore the total responses for this question (n=422) was much higher than the number of respondents overall (n=140).

These total responses do not include 15 survey respondents who chose to not fill out any choices for this question. Some of the other suggestions of information needs included more specific issues related to nutrition such as loss of appetite and weight loss. Also suggested was information needs related to translating the knowledge into practice and ways to become motivated to adopt these healthier lifestyle changes.

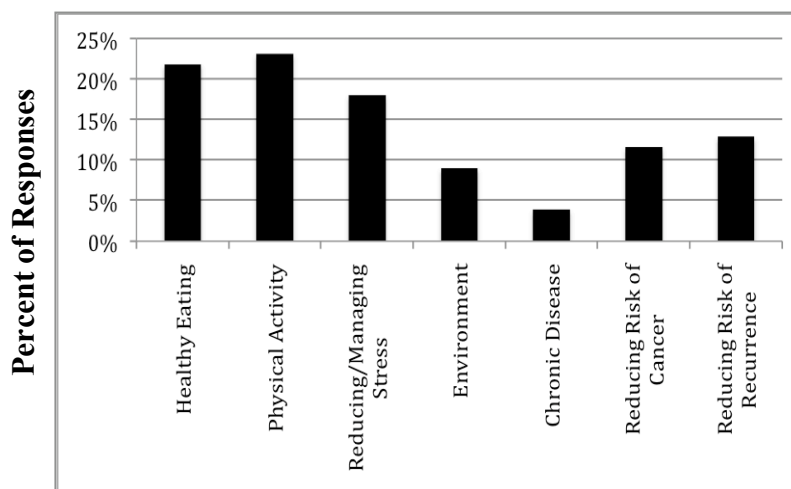


Figure 16 Information Needs for Supporting a Healthy Lifestyle from Making Healthy Life Choices Events (n=422).

Finally, this question was also asked at the Aboriginal Woman and Cancer Think Tank in order to determine what information needs exists in order to support adopting a healthy lifestyle (Figure 17). Information on healthy eating and physical activity stood out as the greatest need in adopting a healthy lifestyle (50% of responses). Followed by reducing stress and a supportive environment (28% of responses), reducing the risk of cancer or recurrence of cancer (18% of responses) and finally chronic diseases (5% of responses). One person did not respond to this question.

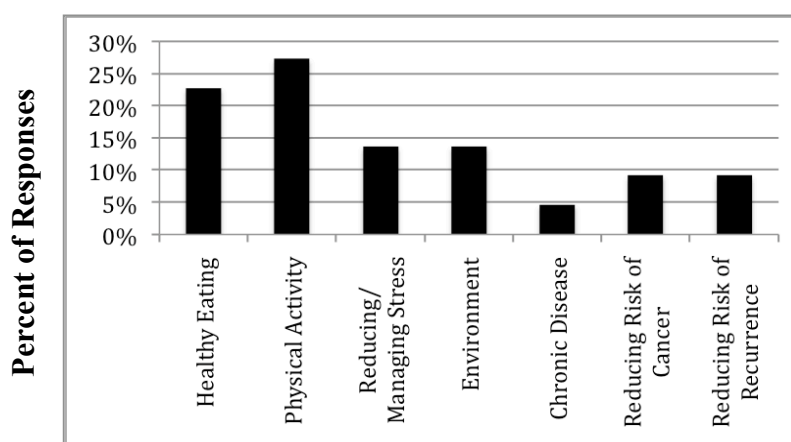


Figure 17 Information Needs to Support Adopting a Healthy Lifestyle from Aboriginal Survivor Think Tank (n=22).

Participants of the Telehealth event were asked whether they found the information provided at the session helpful and whether they would recommend the session to others. All but one respondent found the session helpful (this person added in a category to express that the session was found to be “somewhat” helpful. All respondents stated that they would recommend this session, with only one survey respondent not completing this question.

Program Content. In general the women report positive feedback about the content and quality of the events and activities that were carried out in the current program. These reports pertained the quality and reputation of the speakers, the accessibility of the professionals at the events, and how it impacted those who had attended.

[The SBCN Program Coordinator] had some really good guest speakers in. It was just a really good time to get together and share and find out what exactly is out there. I didn't know half the stuff that was out there. – Advisory Committee Member

I enjoyed the one in Saskatoon when they had some of the scientists there... They're not up in their ivory tower shall we say, but getting down there to be with everybody else. So, I found that [promoted] camaraderie... we're all on the same team. – Advisory Committee Member, Survivor

[The program] touched, it reached out to a lot of people. And there was others there besides. Everybody's always willing to learn something, because there isn't a family that hasn't been touched in some way by cancer. – Survivor (rural, senior)

You can have your doctors up there, you can have your nurses up there, but you really need to have people up there [speaking] that have gone through it. That is the most important, and I think that's an essential element. – Survivor (Aboriginal, young, rural)

Each participant of the Telehealth Education Session was asked to rate the overall on a scale from poor to excellent. As is seen in Figure 18 below, almost all participants rated the session overall as good or excellent (96%). A very small minority of participants rated the session as moderate and fair (4%). One survey respondent did not provide an answer for this question and is therefore omitted from the calculations.

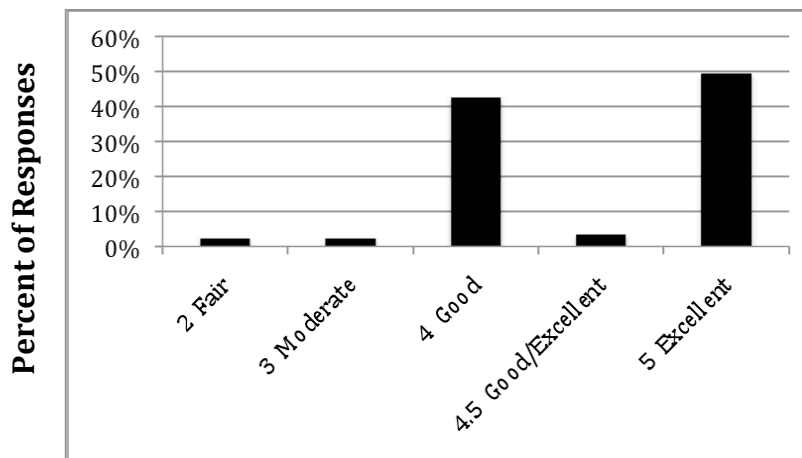


Figure 18 Overall Content and Quality Rating of the Telehealth Session (n=89).

4.3.4 Support

The component of support was often cited throughout all interviews, with survivors and Advisory Committee members alike. This section does not contain survey data collected from events by the SBCN, because support was imbedded in all aspects of the program. While some of the women talked about the support they found at the events themselves, other spoke about the support they received from their families and communities. It is clear that support means something different to different people, but that everyone values it.

[At Connecting the Breast Cancer Community] you could see people having had experiences at very different times in their lives. You can see ones that were newly diagnosed and newly treated; you could obviously tell that they were already going through chemo too. Ones that were survivors for years and years. So these women could be looking at them saying, you know, I'm going to get through this too. – Advisory Committee Member

Just knowing that there are people out there to help and give moral support and encouragement... I think it's great. – Survivor (urban, senior)

My husband was amazing - he did everything. My kids were eleven, seven and four, so they were really young and they helped me through it too. They kept things light, like when all my hair fell out they'd say 'Mom, you're so cute bald!' And my mom and dad and my husbands mom and dad and people that you don't even know were bringing food and flowers and anything, everything. – Survivor (young, rural)

It has been quite supportive having those people there knowing that you're not alone and you have friendship and you have support and you have people that understand exactly the emotions that you go through when you've been diagnosed, when you're going through treatment, how you feel post treatment. – Survivor (young, rural)

Beyond the support received through attendance at events by family members, stakeholders and survivors both reported value in ensuring that individuals have access to organized support groups in their communities. And not only did survivors report needing support themselves, they in turn were to be able to give support to other women going through similar things in their lives.

When I first came into this world I thought, why are there so many different advocacy groups, especially breast cancer. There's just so many groups and organizations, but I think its because part of that is the healing. And for some individuals it's they need to start their own group to get through the process and for others it's okay just to join. You want a young group, and you want an old group and you want a rural group. – Advisory Committee Member

Even two years after everything there's lots of things that pop up. I'd love to help somebody that is just diagnosed, but you don't find out these things, you don't know any other people unless it's [through] word of mouth... It would be nice to form some kind of group. – Survivor (rural, young)

In terms of me trying to find somebody to support me and help me through all of this, even my oncologist couldn't help me...Because of that experience I myself today want to gather as many people um, that I can say, we can reach out and say, 'You know what, I went through it and you can too'. - Survivor (Aboriginal, young, rural)

The support group meant that, thought my husband walked with me through cancer he didn't walk to my shoes. And these people did. They experienced it for their own personal experience, for whatever type of cancer they went through the things that they thought about and the feelings that they felt were very much the same as my own. – Survivor (young, rural)

A large component of supporting women through their journey with breast cancer is ensuring their needs are met. The goal of the Network was to be a supportive body to listen to the needs of these women and implement these into the program delivery, as survivors themselves are the experts of their own experiences.

I had one lady who equated it to driving through a blizzard with your high beams on. You can't stop, you have to keep going, you can't pull over, you just have to keep going and all of a sudden it makes a little, little bit of sense. And I like to think that we're helping them – we're in the drivers seat with them. – Advisory Committee Member

[At the Breast Health Centre a patient] said: 'You know what, could you not speed [the results] up too quickly for me right now? I just need, I need this week to just like think about all this sort of thing'. Well that ...brought me back to what does the patient need? And it's so individual; you can't paint everybody with one brush. - Advisory Committee Member

At the Thinking Learning Caring Survivor Think Tank in Figure 19 below, all respondents felt that their knowledge and experiences were at least somewhat acknowledged at this event. The vast majority of participants (75%) responded that this was acknowledged a great deal, with all respondents reporting at least somewhat acknowledged. One survivor noted that she “felt very much a part of the day.”

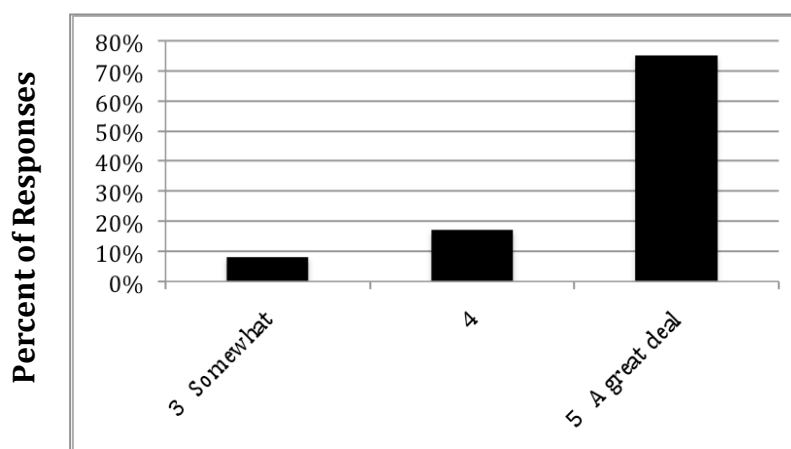


Figure 19 Acknowledgement of Survivor’s Knowledge and Experiences at Thinking Learning Caring Survivor Think Tank (n=12).

4.4 Program Facilitation

The Saskatchewan Breast Cancer Network. Both survivors and stakeholders reported the importance of a Network, such as the SBCN in organizing breast cancer programs in Saskatchewan. Most women found that the Network was instrumental in coordinating the efforts

that had been taking place throughout the province and throughout the country. The scope of the Network was also cited as reaching a large number of people in a population that is very spread out.

A very positive whole, like an action network. So you're not a victim - you're proactive.
– Advisory Committee Member, Survivor

If you stand and drop a stone into the water and, and see the ripples and those circles going out, the Network projects and activities are that stone. And the ripples, are those circles going out, that's the access and the awareness that keeps going. – Advisory Committee Member, Survivor

What I liked is, years ago I saw that there were many people working in this area, but it wasn't a very coordinated effort. And so to me that was the benefit of having a network where there would be a coordinated effort and a consistent message that we could give to the people of Saskatchewan. – Advisory Committee Member

4.4.1 Program Coordinator

All the Advisory Committee members noted that the work of the Network would not have been possible without the dedication and vision of the SBCN Program Coordinator. None of the survivors who were not on the Advisory Committee spoke to this as they were not involved in the facilitation of the program. All the Committee members reported that both Program Coordinators were exceptionally skilled in effectively carrying out the work of the Network.

Always if I needed something – phone [the SBCN Program Coordinator]... Maybe everyone was spoiled by how hard she was working. – Advisory Committee Member

[The SBCN Program Coordinator is] one of the best community capacity workers I've ever met. Years of experience and understanding; how you organize a function and how you organize a meeting. And the soft small 'p' politics of who sits where and what would make somebody more comfortable... And very diligent about the budget. – Advisory Committee Member

Just knowing [the Program Coordinators] I can see why the Network is still standing. It's an important thing and they felt very strongly about it and positively about it and kept on pushing through. – Advisory Committee Member, Survivor

You have to have a passion to do [run the Network]. It was easy for me because I gave birth to that Network. So I knew all its history, all the dynamics, and that is crucial to any Network. – Advisory Committee Member, Survivor

4.4.2 Survivor Driven Initiative

Building on the effectiveness of the Program Coordinator of the Network, many of the Advisory Committee members acknowledged the fact that she too was a breast cancer survivor. These Committee members as well as the coordinator herself, suggested that just as survivor driven initiatives are the building blocks of support groups, her personal experience with the journey of breast cancer could have been a contributing factor to her success in running the current program. She brought not only the survivor's voice to the events, but her knowledge of the needs of cancer survivors in her role on the Advisory Committee.

I think there's a lot of credibility that came from it being survivor driven. Which is why you see the success of the support groups. – Advisory Committee Member

I understood and I had been to the clinics, I had been back in that chemotherapy area, I had mammograms, I had surgery. Just being part of that, it wasn't superficial...It's kind of like somebody telling you about building a building; I was in the basement, I was looking at creating the foundation. – Advisory Committee Member, Survivor

4.4.3 Awareness, Promotion and Dissemination of Information

Many of the women reported that the awareness of the Saskatchewan Breast Cancer Network was limited. Despite having attended at least one event, only two of the survivors were aware that it was the Network who had put on the event, and were familiar with the work of the Network throughout the province. They also noted that they never heard about the events in their communities from the Saskatchewan Breast Cancer Network, but rather through word of mouth from people who had connection in the health field. Advisory Committee members reported that they believed the promotion of the Network to be limited as well as missed opportunities to promote the Network through regional structures.

Because of the support group, this became known to me but I mean there must be other ways of spreading this like through the health region. There must be people in public relations or whatever with sources to get these programs out to rural, (or the information out to) rural communities. – Survivor (rural, senior)

It's finding that group in the community whether it's the public health nurses or home care nurses or somebody who's going to put the poster up and talk about it at a staff meeting. And that's the biggest challenge we have ... to go beyond an Advisory Committee with representation from some organizations and to try and imbed itself more in the regional structures. – Advisory Committee Member

I think maybe if [the event] was advertised a little bit more that maybe more people would've come. [I] just found it in the paper in a little corner of the paper and my friend's daughter works at the hospital so she knew about it...But I don't think very many people actually knew it was happening. – Survivor (young, rural)

[I] had to do the footwork to finally find somebody and then all of a sudden find out that hey, [the SBCN] existed out there? Well what happened to me? Where [was the SBCN] when I was going through this at such a crucial time? – Survivor (Aboriginal, young, rural)

After each event, the Program Coordinators made themselves available to field follow-up calls and e-mails from participants who requested more information, either on the event topic or beyond the scope of the current program. These individuals were also directed to sources of information or mailed event slides or follow-up documents. For example, following the Telehealth Education Session, the SBCN received numerous email requests for more information on the topic of the presentation. These individuals were referred to the Canadian Cancer Society cancer information service toll free number to respond to lingering questions beyond the scope of the presentation information.¹¹ Also following the development of the *Healing Leads to a Healthy Lifestyle* document, an outcome of the Survivor Think Tank Recommendation Document, it was disseminated to participants, partners and survivor support groups electronically. Additional hard copies were also disseminated upon request by the SBCN.

4.4.4 Program Challenges

The women reported a large array of challenges that they felt interfered with the potential success of the current program. These concerns ranged from the challenges of working with grants, struggles collaborating with the Health Regions, and the interference of H1N1. However many Advisory Committee did mention that despite the setbacks, the Network did continue to implement the current program to the best of their ability. Although some events had to be moved around and some compromises had to be reached, almost all the events were eventually

carried out. The survivors did not have any comments on the challenges in implementing the current program as they were participants and generally not aware of the specifics of the program facilitation.

The grant process was frustrating. That it's really hard to want to do all this stuff for your community and for the people that you represent but you would apply for a grant and it would take six months to get your money in place. But your proposal started three months before you got your money. How do you put on a Lunch and Learn when you have no cash? – Advisory Committee Member, Survivor

Often times just because something is our priority with the Network, it's not necessarily a priority of somebody else's. And so that was a big struggle because we thought it would be an easier job than what it was to work with the Health Regions. – Advisory Committee Member

After having the Survivor Think Tank in September and sorting that out it actually gave us a bit more time to revamp what we did down in the Weyburn and Estevan area. So, although we didn't do it when we wanted it, when we did do it I think we actually made it a better event because we had some time to fix it up and do it a little bit differently.
- Advisory Committee Member

4.4.5 Program Improvements

Scope of the Program. As the current program was implemented and challenges were met, the Program Coordinators became more cognizant that perhaps the scope should have been scaled down. One survivor felt that her community didn't receive sufficient support in hosting the event locally and that more support should have been offered to smaller communities by the Network. Finally, the SBCN Program Coordinator also noted the benefit of having the current program evaluated by the researcher and research supervisor as she felt it was an important way of having those with specific program evaluation expertise guiding the program to ensure optimal satisfaction.

I think that we have to start smaller, we had too big of a goal to work with more than one or two health regions. Maybe you need to look at working with one Health Region and talking to them ahead of time to see if it's going to fit. And then if that's a success then you can kind of use it as a pilot and then say to other Health Regions, it worked.
– Advisory Committee Member

The sad thing for is that I don't know if they'll ever be enough resources or manpower to get us to where we really need to be. – Advisory Committee Member, Survivor

We were in charge of looking after you know, booking a place and making sure equipment was there and things like that... We looked after providing the lunch, which the Saskatchewan Breast Cancer Network paid for... If it was their program, I would have liked to see them come in and do the whole thing. - Survivor (rural, senior)

Since 2000, this is first time that we had an evaluation advisor. I think that also was a huge bonus in guiding the project and creating satisfaction, because it was a broader piece and is a huge complement to the Network compared to other years...Having another unbiased look at the project that wasn't the primary partners guiding or myself. – Advisory Committee Member, Survivor

Including all Ages. One criteria for interview participants was their age, as was defined in the proposal for the program implemented by the final program. Most women found that the information and education gained from the events was applicable regardless of the age of the survivor. There was noticeable representation at many of the events from both the young and senior survivor populations.

[The survivors ranged] from the 24 year old to the 75 year old, from people who are a couple weeks out of surgery to people who've been a survivor for many years. And I think that's good – there's lessons for everybody there. – Advisory Committee Member

Conversely, one Advisory Committee member who was also considered to be a very young survivor in her 30's felt that there was not adequate representation of even younger women. She noted that women under the age of twenty-five deal with issues that may be different than young women between twenty-five and 50 years old which need a greater focus in programs.

I have met over this last six years so many young women that were under the age of 25, and their struggles are very different from a forty- year-olds struggles... I guess the younger woman maybe wasn't represented. I'm past having kids and I'm past that dating and getting married, but a lot of the women that I ran into were just actually in that stage. They either had just gotten married or were thinking about getting married and the whole child issue. You know, that was a big one. A really big one. – Advisory Committee Member, Survivor

I found out that chemotherapy stops that process. And it put me into menopause immediately. And so, when I was going through the process after chemo of healing, I actually went through menopause at the same time. It was a nightmare. – Survivor (young, rural)

One young survivor also noted that the needs of older women do differ markedly from the needs of younger survivors. Both these groups of women have significant challenges, but these should be independently addressed in order to optimally meet their needs.

Sometimes the older [women] are doing it on their own... and they don't always have the ability to maybe get to treatment – they have to really rely on members in the community to help them that way... I think that they have a little bit more of a challenge physically because your older your body doesn't sometimes respond to treatment as quickly or it suffers under the rigorous treatment that they do have to get. – Survivor (young, rural)

4.4.6 Future of the Saskatchewan Breast Cancer Network

The future of the SBCN is uncertain given that the Program Coordinator has retired from her position, and no one has been hired to fill her role. Without dedication to the Network and role in securing funding, the Advisory Committee is left without knowing whether the successes of the program will be sustainable.

Without a coordinator, without funding, I'm not so sure we have a sustainable Network. – Advisory Committee Member

I'm hoping that the Network will continue and will be able to figure out leadership there, and be able to push on. I think it's an important, I think it's got a necessary role and it's important work to keep this broad province connected. Because it's such a primarily rural [province] in comparison to some of our other provinces where majority of people are in the big cities. – Advisory Committee Member

I'm kind of sorry that [she] is not here, because she was, the one that sort of got it going. She was able to pull it all together and get the quality speakers and everything. And with her not being there, I hope it's not going to fall apart. – Advisory Committee Member

4.5 Unintended Impacts

4.5.1 Responding to Regional Characteristics of Saskatchewan

Program implementation in Saskatchewan has noted difficulties that may not be as significant in other regions. The population in the province is very dispersed and severe winter weather makes it challenging to serve these remote or isolated communities.

It's always frustrating in Saskatchewan. You have those little windows of September/October, May/June where you have to deliver a whole years worth of programming because people can't travel and the weather sucks. – Advisory Committee Member

When you look at Saskatchewan our breast cancer community, it is spread. It is not huge pockets, clusters. That's why we're constantly facing the issue of say support groups, because we don't have large population. – Advisory Committee Member, Survivor

Rural and Urban Survivor Access to Services and Resources. The program attempted to reach rural communities, which may not have otherwise had opportunities to have educational events implemented close to home. As the majority of the service providers are located in the larger centres of Regina and Saskatoon, this would mean a significant amount of travel for women diagnosed in rural communities to commute. This travel was not only relevant during the clinical treatment of cancer, but ongoing access to survivor services and support. The current program attempted to bring this information to these rural communities. The rural survivors interviewed perceived the experience of urban patients and survivors to be easier as it was presumed that they had greater ease in accessing needed resources and services.

Urban people have more opportunity to learn, more opportunity to attend some of these programs, quicker access to solving some of their problems or questions, than we out in the rural area do. - Survivor (rural, senior)

I think the first year when I was diagnosed we made twenty-six trips to Regina which was tough. I mean when you're going through treatment it's two hours away. So that was hard. I did all of my Herceptin treatments in Estevan and I did three chemo treatments in Estevan too which I loved because I didn't have to travel that day...my family could be there for me when I was done. – Survivor (young, rural)

This program improved ... increasing the awareness and access to information by going to different communities that had never had projects or workshops done by the Saskatchewan Breast Cancer Network. – Advisory Committee Member, Survivor

The workshops that were done throughout the province, which was focusing on the rural population, which is huge. That's a challenge in Saskatchewan because we have a huge rural population. And bringing it to the rural population versus asking them to come to our two large centres (Saskatoon and Regina), creates a wider understanding and improved access. – Advisory Committee Member, Survivor

As the current program sought to reach out to rural survivors, the intended outcome would have been an improvement in their perception of whether their needs were being met. The Advisory Committee members reported the challenges associated with being a breast cancer survivor in a rural or isolated and the awareness of their unmet needs. While the survivors did feel that this program was a good start in reaching out to under-serviced communities, the current program was only able to implement their program in a limited number of communities and for a fixed term, which would have left many survivors without their information and education needs met. It was reported that the needs of rural survivors do not differ markedly of those of survivors living in urban communities, but the restricted accessibility for rural residents creates additional challenges for these women.

There's not difference in the patients or survivors, between urban and rural. We're all faced with the same questions and problems...I think that's the same for everybody that it doesn't matter where you live. - Senior (rural, senior)

[At the ThinkTank] you had rural, young sitting there and urban and at the end saying, 'you know what, our issues are pretty well the same' ... They found out that it wasn't totally better to be an urban survivor. There was challenges on both sides, and I think that created more confidence and acceptance. – Advisory Committee Member, Survivor

The survivors access that information and education because we should be the ones that have the connections and make those connections for them. Especially the women and it's predominantly women we've met in rural Saskatchewan. – Advisory Committee Member

Aboriginal Populations. Another focus of the current program was to reach out to Aboriginal communities in the province who may have barriers to accessing breast cancer information and services, similar to residents living in rural communities. One survivor

interviewed identified herself as being Aboriginal and reported the action of the SBCN quite differently than Advisory Committee Members.

Aboriginal needs aren't that much different from the rural remote [needs], but their perception is that they are very different. And I think you just have to accept that and program based on it. – Advisory Committee Member

Sometimes [Aboriginals] just are invisible. Some people in our community just seem to be. Some cultures are just not front and centre... everyone's in the same boat. – Advisory Committee Member, Survivor

The goal of the Network with the Aboriginal community [was to] bring them on board so that it's not just us and them. For the Aboriginal woman to see that being diagnosed with breast cancer, whether you're Aboriginal, senior, rural, younger –it's very frightening and a lot of the same things that flash through their minds. – Advisory Committee Member, Survivor

[Working with] Aboriginals, that's an ongoing work in progress; creating relationships, creating trust, getting access and awareness. And the Saskatchewan Breast Cancer Network partners have recognized that looking at the Aboriginal community most often breast cancer is not a priority. There's huge issues for the Aboriginal community too. – Advisory Committee Member, Survivor

If I could have seen another Native person walking through that door and maybe going through something I was going through, or somebody that had already been on the road to recovery, I know that I wouldn't have stressed myself out the way that I did. – Survivor (Aboriginal, young, rural)

We're not all from Regina or Saskatoon; we're from little communities. Come to us, have a road show, come to us and I'm sure you would find that much more people. There also has to be a cultural component attached to it, because a lot of these people were raised that way. And some of them really look towards surviving it that way. – Survivor (Aboriginal, young, rural)

4.5.2 Addressing Survivorship: Meeting the Needs of Survivors

The concept of survivorship is significant in the culture of all cancer survivors. They are unified by their shared experiences and journey of diagnosis, treatment, and transition to identifying as a survivor. This personal evolution appears very different today than it did years ago as more and more women are surviving past the 5-year threshold.

People used to think when you're given a diagnosis of cancer, say maybe twenty years ago, that equated death. Well now that's changed. – Advisory Committee Member

Survivorship refers to the time from diagnosis throughout the remainder of the person's life. How woman copes or overcomes each of these stages defines is different for every individual. A woman's journey through cancer is made up of each of these battles, and culminates in her overall survivorship. As made evident from the reports of Advisory Committee members and survivors, each woman's needs are different at the various stages, and each woman approaches meeting these needs in different ways.

I have a two-story home and my bathrooms on the second floor and I learned that I had thirteen stairs I didn't know that I had and I counted. And when I made it up to the top step without collapsing some days, it was like 'yay!' - Survivor (young, rural)

Some people roll up in a ball and wait for something bad to happen. It's not the end of the world. I call it 'two bumps on the road of life'. So, I refused to lay down and be victimized. I was going to do what I could to make it better and so far so good.
– Advisory Committee Member, Survivor

It was incredible to listen to the stories of the different women, telling us how they've traveled on their journey and what needs were not met at that time. – Advisory Committee Member

Until you've been kind of cornered with that kind of a health crisis, I don't think you understand fully how important life is. And how you really forget about the petty stuff and the stuff that people complain about, the things that they worry about... It really puts your life in perspective. – Survivor (young, rural)

Making meaning of your experience is a key element of survivorship and reflects how individuals construct the world around them with their new identities as survivors. As is evident in Figure 20, all survivors who attended the *Thinking, Learning Caring Survivor Think Tank* found the session to be at least moderately meaningful, with the highest frequency finding it meaningful to “a great deal” (67% of respondents). All the respondents noted that this event was at least somewhat meaningful to them. Although respondent notes that this session did not generate “more do-able ideas” as had been hoped, the importance of putting principle into practice was highlighted. Overall, survivors shared that the day showed “just how much [they]

need these Think Tanks and how we all feel the same way about a lot of different and important issues.”

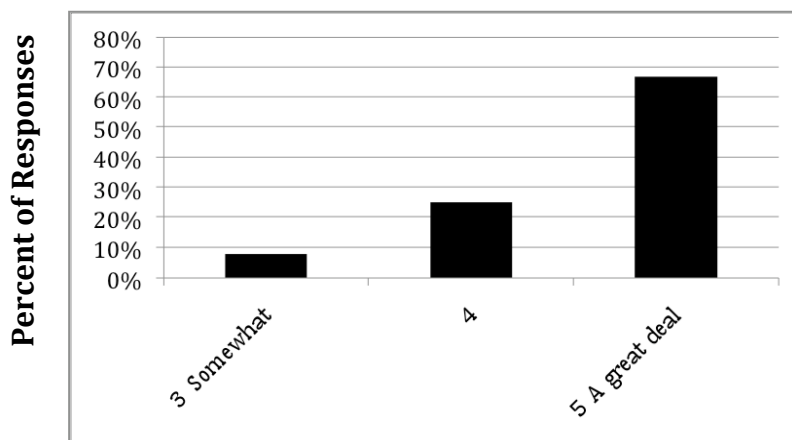


Figure 20 Meaningfulness of the Think Tank Event (n=12).

Similarly at Connecting the Breast Cancer Community event, most of the respondents (99%) found this event to be at least somewhat meaningful as seen below in Figure 21. Though not depicted, this scale ranges from 1 (not at all) to 5 (a great deal). The general sentiment from the comments to this question was that it was encouraging to have the opportunity to share information in the format of this event. “It took years to get where we are in the breast cancer community [and] these types of events keep us current and allow for the nurturing of our network connections.” Some participants noted that they were affected by the attendance at the event, as they believed it to be low. One respondent suggested “more media advertising prior to event while another believed that because of the “busy time of year to attend, attendance [may have been] down because of it.”

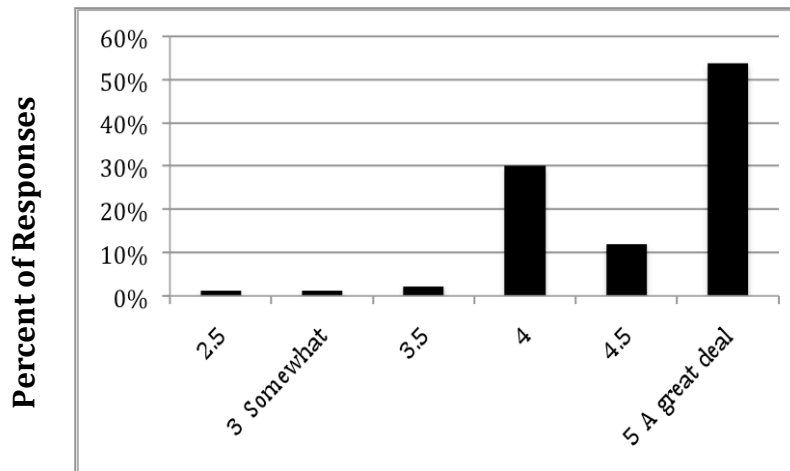


Figure 21 Extent to Which the Connecting the Breast Cancer Community Event was Meaningful (Saskatoon and Regina, n= 93).

Transitioning. One of the components of survivorship is moving between each of the stages; from diagnosis through to living as a breast cancer survivor. The following accounts represent the stories of the Advisory Committee members and survivors who recognized the challenges of changing identities and needs.

There's so much after diagnosis, right? And, so there's a step then from diagnosis to treatment. But then there's this huge leap of what then, right? – Advisory Committee Member

Sometimes it's hard because you have some kind of medical thing and you think 'Oh no, is it coming back?' Sometimes it feels like, okay you're done and over with [it] now, you have to move on. But it's hard. It just feels like they kick you out of there and then that's it. – Survivor (rural, young)

I found it hard that when I was done all my treatments they just kicked you out of there and 'see you in a year for your check-up'. But after you finish all your treatments you just need that extra reassurance that it is okay to move on in life now and I felt that sometimes I didn't get that. – Survivor (rural, young)

This high school kid came to the backdoor [doing fundraising for school] and I was cooking supper, and I didn't think to put my wig on, I just opened up the door. And I scared the bejeepers out of him! Honestly the look on his face. And I apologized to him, I said 'I'm sorry. I'm at home, I don't think about it.' But you don't realize how much of an impact that that has on other people. – Survivor (young, rural)

Acceptance. Survivors reported feelings of accepting their diagnosis. Perhaps acceptance is a factor of a transitioning identity to a breast cancer patient or survivor. Among survivors interviewed, none expressed any anger related to their diagnosis.

I didn't say 'why me?' because why not me? Other, better people than I have had these problems and there's so much of it that you're not surprised if you're diagnosed that way. – Survivor (urban, senior)

I'm, actually I know it's silly to say, but I'm glad I got breast cancer because it's changed me. You're a little more appreciative of things; the view after cancer is much different than before. And I can help some people... after you get over the terror. You can feel good about what you do and how you do it and who you do it for. It's a bumpy road, but it's a good one. – Advisory Committee Member, Survivor

I have to thank my family, my children and my husband to allow me to go through something like that. It was a family illness, it really was. I am so good today. I don't feel alone...and I'm not ashamed to talk about it. I no longer feel that I'm damaged goods. – Survivor (Aboriginal, young, rural)

Luck. Despite being among the statistics of women diagnosed with breast cancer, and those who have continued to survive this illness, the women reported feeling lucky about their experiences. These reports reflect a post-cancer perspective and a general belief that things could have always been worse. From these accounts it appears that the cancer journey experienced a realignment of how they assessed their lives.

I was lucky I didn't have to have the harsh treatments of radiation and chemotherapy. – Survivor (rural, senior)

I'm in good shape for an old lady. I've been able to get around and do things and I am sorry for other people that can't do that. I have empathy, great empathy for them. But as far as my own life is concerned, it's been fine. - Survivor (senior, urban)

I know it's silly to say, but I'm glad I got breast cancer because it's changed me. You're a little more appreciative of things; the view after cancer is much different than before. And I can help some people... after you get over the terror. You can feel good about what you do and how you do it and who you do it for. It's a bumpy road, but it's a good one. – Advisory Committee Member, Survivor

Healing. Although healing is a construct, which is interpreted differently for each woman, many of the women spoke to how they experienced this. Whether it is emotional or physical, healthy was reported as a significant stage in the cancer journey. Healing happens at different times and in different ways for each woman.

I decided on a bilateral mastectomy with immediate reconstruction, which I'm very pleased. Because I just couldn't have one breast removed and then wait for the next bad news. That was my theory; get it all and get on with life. – Advisory Committee Member, Survivor

There were many individuals that I've met over the last ten years who have had a second bout of cancer in that ten years and some who didn't survive. And others who are doing really, really well... Healing can mean different things to different people and getting to the point when you can get out of bed everyday might be just healing to somebody. – Advisory Committee Member

4.5.3 Future Strategy: All Cancers

Throughout the current program, the SBCN began to discuss broadening the scope of the Network beyond breast cancer to include all women's cancer. These discussions happened at the Advisory level, but similar sentiments resonated among survivors. Especially for those in rural communities, it is not efficient to have a different cancer group for each type of cancer, when the population is relatively so small.

We didn't just spearhead [the support group] for breast cancer, like we opened it up because it's a small community, to, we opened it up to all types of cancer. - Survivor (rural, senior)

We've done these events before, but then we're kind of being very exclusive only focusing on breast cancer. We know that when you start going out in the rural areas that there's women out there with other types of cancer - so we're excluding them by saying it's for breast cancer only. And national, in fact, talked about the move towards all cancers. – Advisory Committee Member

Its cancer in general and how that affects not only the individual but families and communities. And when you live in a small town, just about everybody knows everybody so, it is really important to know that you have that kind of a support or a place that you can go to talk about these kinds of things. – Survivor (young, rural)

Additionally, as the events that were run in the smaller communities focused on healthy lifestyle, these messages can be translated for people with all types of cancer. Many people with breast cancer have very similar concerns and stakeholders no longer feel it is necessary to restrict such a program to just those who are breast cancer survivors.

I'm really pleased that they're looking at broadening the scope so it's not just breast cancer. Although breast cancer is important, there are other types of cancers that women have. A woman who's diagnosed with breast cancer has a lot of the same concerns as a woman who's diagnosed with any type of cancer. – Advisory Committee Member

I think the strategy [is] to tie it not so much to breast cancer but to sort of women's health... Everything that you would do to prevent and survive your breast cancer are things that would help you with your heart problems or your diabetes or whatever... You go to these communities and there might be a man there with prostate cancer who's all alone as well. It's tough. – Advisory Committee Member

5. DISCUSSION

This chapter broadly addresses the role, successes and challenges of the SBCN in bringing together partners and collaborating with key stakeholders and survivors. The factors that affect this grassroots organization in implementing survivorship care will be presented in its Canadian context. The first section of this chapter discusses the significance of the evaluation and its contribution to the current body of research. The second section highlights the role of the SBCN as a provincial organization and its benefits and challenges in offering programs to meet the needs of survivors. The third section presents the limitations of the evaluation and of the program. The fourth section focuses on recommendations for future programs and research followed by a brief conclusion.

5.1 Significance of the Evaluation

The breast cancer death rate in Canada is currently the lowest it has been since 1950, with 87 percent of Canadian women diagnosed living past the five-year survival mark.¹ This evaluation of the SBCN's program *A Thinking, Learning and Caring Collaboration: Promoting a Healthy Lifestyle*, contributes to the growing research on survivorship among women who have had breast cancer. There is limited research currently available on the specific barriers faced by breast cancer survivors, or any cancer survivors for that matter, towards attaining a healthy lifestyle after treatment.

While some experimental research studies have compared health behaviours of survivors to the general population, little evidence exists regarding unique challenges faced by the many different groups of women who make up the survivor population. Currently the research either empirically describes current health trends among survivors, or expresses contention between survivors and traditional medical care. As the length of survivorship increases (i.e. from the time of diagnosis to the end of life), long-term health issues have emerged as a public health concern.²⁰ In the case of the current study, such issues are related to the long-term health behaviours employed by survivors. By identifying the barriers, breast cancer survivors face to effectively change their healthy behaviours towards a health lifestyle, specific areas of improvement were identified.

Limited research exists surrounding the experience of transitioning from patient to

survivor and beyond, and instead focuses on diagnosis and treatment. Graduating from the clinical treatment of cancer often means a loss of a formal survivorship action plan and care, which is where the role of community health care allies become significant.⁵ Although the SBCN has been an active member of the Saskatchewan breast cancer community for many years, the current study marks the first time one of their programs was formally evaluated. This evaluation will hopefully contribute to the capacity of the SBCN and partners to deliver effective programs by building on past successes and learning from limitations.

Given that women are living longer than ever before following diagnosis, clinical treatment represents only a fraction of survivorship. The suggestion that after cancer the life of the survivor returns to normal is just not true.² There is no going back to the way things were prior to diagnosis, and for this the SBCN continues to support survivors in redefining what is normal, and how to continue to lead their lives in healthy and productive ways under the auspices of their new identity.

5.2 Contribution of the Saskatchewan Breast Cancer Network

The current program of the SBCN recognized the lifelong psychosocial process of survivorship, and moved beyond the narrow definition of a survivor as being cancer-free for at least five years. Women at all stages of survivorship were given the opportunity to be the experts on their own experience, as program facilitators acknowledged their needs and encouraged them to influence the program content. This approach facilitated the development of a common vision between survivors and the key stakeholders responsible for their long-term care and support. By coming together to unravel the needs and challenges faced by breast cancer survivors in Saskatchewan, this program afforded providers with a unique opportunity to learn about survivorship from those who had experienced the journey.

5.2.1 Program Implementation

Central to the current evaluation was the development of the program logic model. While the model did closely mirror the actual events and activities that took place, it was the excellent work of the program coordinators that made the program so successful. Significant challenges exist within the grassroots movement in addressing women's needs. Anticipated by organizations such as the SBCN, these include term funding and reliance on health regions. In the current

program, the weak collaboration with the Health Regions, in part due to the H1N1 outbreak, made it difficult for the SBCN to continue to implement some of the events as initially proposed. However, the program coordinators compensated for this challenge by creating additional events carried out later in the course of the program.

Throughout the program it seemed clear that meeting the needs of survivors was paramount in directing the course and content of events. Katsiper et al.¹⁸ found that many breast cancer survivors feel that they have to advocate for their own health and that a survivorship care plan is an important supplement to the active participation of their oncologist. The program offered an opportunity for survivors to learn how to make positive lifestyle choices in a non-clinical setting. By leveraging existing programs and services throughout the province, the SBCN maximized its scope, effectively bringing together survivors and stakeholder to improve survivorship quality of care and health outcomes in Saskatchewan.

5.2.2 Educate and Inform Survivors

Several tools have emerged in the literature to bridge the gap of unmet needs in transitioning from patient to survivor and beyond, including support for survivorship focused education and training.³⁷ Since community based organizations such as the SBCN are rooted within the community, they are well suited to identify the needs of target groups, such as those identified by the SBCN. By increasing breast cancer survivor's awareness and access to education and information, the SBCN was able to promote a healthy lifestyle and offer the tools to make this transition possible.

Of the four components of the program, support presents as an overarching theme. A supportive environment becomes the backbone that will then facilitate the education, information and networking opportunities, which, in turn, contribute to an effective and comprehensive survivorship program. A study by Allen et al.⁵ found that while women experience fear and distress as they transition from patient to survivor, they also go through positive changes in attitude and increased emotional strength. This is consistent with the current study, which elicited accounts of women who learned about their own emotional and physical capabilities. The survivors interviewed all had the support of their community or of their families at some point during their survivorship journey. Many of these women accepted their diagnosis without self-pity and have since become advocates for the breast cancer community. They recognized

their need to be connected and to support others going through similar experiences by engaging in activities such as, organizing a support group in rural Saskatchewan, sitting on the SBCN Advisory Committee, speaking engagements, and peer support.

These supportive needs however, are markedly different for each of the populations targeted in the current program. For example, Aboriginal healing rituals and ceremonies were found to be important aspects of cancer prevention and treatment, yet were often not recognized or accepted by doctors.²³ The SBCN acknowledged this need and held an Aboriginal Survivor Think Tank, co-chaired by members of the Aboriginal breast cancer survivor community. This event featured a Talking Circle and was designed to respect the unique needs of Aboriginal breast cancer survivors in order to create an environment in which they felt they could share their stories.

Another group of women who have unique survivorship needs are those who live in rural communities, with limited access to cancer care services. Gray et al. found that access to health care information, support and services was believed to be a primary concern by breast cancer survivors from rural Canada.²⁵ The SBCN collaborated with small support groups in various rural communities and brought speakers to these communities, who may not otherwise have been able to locate where the needs were in the province. Within each community, the needs of women vary depending on their age. In fact, one study found that older survivors have better emotional functioning and less psychological distress than younger survivors.²⁹ The SBCN acknowledged that programs need to target issues relevant to a woman's life, in order to further engage each survivor.

Cancer survivors are more likely to engage in healthy behaviours, such as weight management through physical activity and smoking cessation.^{20,35} However, these positive behaviours need to be integrated into the lifestyle of survivors to improve their sustainability. To help ensure the longevity of these changes, the SBCN facilitated self-care for survivors. This was done by providing participants with additional resources and by developing a network of services and providers who could continue to support these behaviours beyond the scope of the formal program.

5.2.3 Leveraging the Community

The premise of the current program was to facilitate the collaboration of the members of

the Saskatchewan breast cancer community. This included improving the healthy lifestyle education and information of the general public, specifically by leveraging the breast cancer community. Although not explicitly included as a program component, communication is an important condition that allows for the other learning to take place. Communicating with and educating providers and patients to clarify roles and responsibilities pertaining to long-term care, is one of the strongest themes that emerge from the literature on survivorship.³⁷ There are many different non-governmental organizations across Canada that provide information and support for cancer survivors, with several focusing on breast cancer alone. Many of these community based health organizations, such as the SBCN, provide non-clinical cancer support throughout diagnosis, treatment, and survivorship. However, research exploring the roles of non-medical providers in health communication is limited.⁴ As the health care system does not approach cancer survivorship in a holistic way, it will increasingly become the responsibility for organizations such as the SBCN to fill in the gaps and meet the needs of women throughout survivorship.

The SBCN's program abolished the dichotomous relationship between providers and survivors and empowered each participant to be an equal advocate for positive change. By including medical professionals as event participants and not just presenters, they were given the opportunity to step away from their traditional position behind the podium and become a member of the audience. By changing their physical point of view, providers were able to conceptually become a member of the breast cancer community and learn from the event as any participant would. Kroenke et al.⁴⁰ suggested that clinicians should look to be involved with women's social networks to help ensure access to necessary care and resources. The SBCN did just this, providing a social network for clinicians and other health care workers to not only teach about long-term health outcomes, but also to learn about how to better meet the needs of their patients.

By facilitating communication between survivors and the medical community, the SBCN acknowledged that being disease free doesn't necessarily mean being free from disease. That is, once the physical symptoms of cancer disappear, survivors still face many associated physical and emotional concerns, which may fall outside the boundaries of traditional follow-up medical care. In a qualitative study conducted by Kantsiper et al.,¹⁸ focus groups were conducted with survivors, oncologists and primary care physicians to explore transitions to follow-up,

communication, patient needs, and provider roles. This study found that these three groups all wanted to collaborate in survivorship care planning, and believed that a communication tool would be a valuable mechanism for reaching this objective. The authors highlighted that a research need exists to acknowledge psychosocial elements of survivorship to ease the transition.

Although it is one of the most important variables in the patient–provider relationship, little literature exists exploring communication processes between non-physician providers and patients.⁴ At the Connecting the Breast Cancer Community events, the SBCN facilitated communication between the three groups and even went further to include non-medical health care providers in the conversation. Survivors and stakeholders alike appreciated the unique opportunity to have everyone in the same room taking ownership over long-term survivor care.

The SBCN's focus on networking and collaborating made this program an important addition to survivorship programming in Saskatchewan. Because it was not possible to reach out to every survivor in the province, The SBCN tried to coordinate the many efforts happening across the province. Whether a small rural independent support group or the Breast Health Centre in Saskatoon, the SBCN saw each as a valuable member of the Saskatchewan breast cancer community. Even without elements of sustainability in place, the SBCN made a big impact on breast cancer service providers and health care workers throughout the province and established strong connections. Instead of the haphazard approach of many support groups, the SBCN created a comprehensive network of survivors, educators, Health Regions and service providers, and even without the continued efforts of the formal network, long-term relationships, which began in the current program, may continue to exist. The learnings of the Advisory Committee Members and other partners may continue to influence their future work, as this program gave them the opportunity to learn how to better direct their services to meet the needs of the community. These positive outcomes are apparent even given the lack of elements of sustainability in place. With a cancer survivor serving as a positive agent of change and facilitator along with the security of financial support, the model used by the SBCN for the current program holds much promise for the future of survivorship care.

Though only implemented for a year, the program was already successful in creating some positive links with Health Regions in the province. It also made a concerted effort to include hard to reach survivors, who may be overlooked by larger organizations. This was done by collaboratively implementing healthy lifestyle education events, which took place in four

communities. Being a grassroots organization allowed the SBCN to assess which groups were in the greatest need of survivorship care and work from the ground up to meet these needs. The SBCN's program was not implemented in a void of other breast cancer services and support, and for that reason the broad range of goals were possible. The SBCN was able to propose a broad range of goals due to its intention of leveraging existing programs and services throughout the province. While competition for services and overlapping mandates may affect grassroots initiatives, the SBCN called on these other services to be a part of their wide reaching network.

5.2.4 Bringing Together Stakeholders

Through representation on external committees provincially and nationally, the SBCN was able to increase awareness of their work. There is a significant value in learning from the successes and challenges of breast cancer community stakeholders throughout the country in order to improve the potential for positive outcomes in Saskatchewan. Bringing together local, provincial and national stakeholders to improve access to breast cancer information and support survivors and their care providers across Canada was the motivation behind the Canadian Breast Cancer Network's *Model for National Collaboration*. As previously discussed, the evaluation of this capacity building model found that being in a national network of stakeholders not only made members feel their work was validated, but also improved their professional capacity. This is consistent with the SBCN's program, which left stakeholders feeling successful in learning about initiatives happening throughout the province and having a larger network of services. This model however, may downplay the role of breast cancer survivors in establishing best practices. In this study, the survey data collected from survivors provides a new direction for such collaborative models.

Not only did the SBCN facilitate collaboration at their events, they created opportunities for future collaboration once the program ended. A key example of this was the intention to become aligned with the national move towards broadening the scope of the SBCN to include women with all cancers. The SBCN was successful in facilitating a common vision among key stakeholders and impacted how service and care providers perceived survivorship. A greater understanding and appreciation of this survivor-driven model of delivery is a key sustainable outcome achieved by the program, as well as significant learning among participating stakeholders.

One proposed indicator of success of the program is whether there was an increase in the perception of the SBCN as a provincial leader in promoting a healthy lifestyle. It seems as though many of the survivors were not aware of the role of the SBCN or did not even realize that the SBCN had facilitated the event attended. However, while it is noteworthy that recognition was not achieved at some level, stakeholders and researchers nevertheless acknowledged the SBCN as an advocate for the needs of breast cancer survivors. The SBCN was able to empower women to make positive life changes towards leading a healthy lifestyle thereby reducing the risk of recurrence and health complications. Although the SBCN believed that recognition of their role in the province would lead to improved outcomes, what was most significant was that the events were carried out in an effective manner. Which group facilitated these events was seemingly less important than the message that was delivered.

Throughout the breast cancer community, locally and nationally, there are competing messages, which many survivors find difficult to distinguish. Many different groups with diverse mandates exist in the breast cancer community, and survivors find it challenging to distinguish the role each one plays. The SBCN clarified overlapping mandates at the Connecting the Breast Cancer Community events and painted a cohesive picture that supports and enables survivorship. Overall, the current program was successful in bringing together local, provincial and national stakeholders and in facilitating conversation between providers, survivors and community. Despite inconsistent messaging, the SBCN established a common vision; empowering breast cancer survivors to control the course of their survivorship.

5.3 Strengths and Limitations

Several strengths and limitations should be considered in the current study. One strength of this evaluation resides in the strong partnership that was established between researchers and the SBCN. Both parties were respectful of the evaluation process and sought to find a balance between the needs of the SBCN and the research perspective and rigour. Ongoing feedback was also received from the SBCN Program Coordinator and Advisory Committee Members regarding the development of the program logic model and organization of the results. By including these stakeholders in the research process, any misinterpretations were avoided and the focus of the evaluation was refined.

Another strength is in the simultaneous collection of survey data as the program was unfolding. This minimized potential bias in participants' ability to accurately report details relating to their experience at events. Also, the high return rate of surveys from the events as well as cooperation from Advisory Committee Members and survivors to participate in an interview provided the researcher with a broad range of experiences represented in the data. This community support for the evaluation provided an excellent depiction of the various opinions of event participants and facilitators in the program.

The limitation of this evaluation is in part related to the nature of real life research where events occur in unplanned ways and mistakes are made. The information collected by the self-report surveys was limited to the questions developed by the SBCN. The scales used on the surveys developed by the SBCN left some ambiguity for the respondents, which affected potentially the interpretation of the answers. For example, for some questions respondents created categories by marking their response in between two numerical categories on a Likert scale. These responses were organized with the most consistency possible and categorized as half numbers (i.e. 2.5, 3.5, etc.). However, it is difficult to assess what the respondent's true intention was, or whether they had in fact intended to choose one of the categories but it just appeared to be in the middle.

One consistent survey was not used throughout the program, and the questions changed between events. Part way through the program, a second completely different survey was developed and used in order to gather information pertaining to healthy lifestyles. While the Program Coordinators likely introduced this survey in order to gauge current knowledge around healthy lifestyles and additional information needs to support these modifications, these data did not seem directly relevant to the current evaluation. Ethical concerns, length of survey and anonymity may also have limited the range of questions the researchers may have liked to ask under ideal circumstances.

Another key limitation of this evaluation was that demographic information was generally not collected from the events. By overlooking the significance of such questions, pertinent information such as the number of men at events, the age of survivors, or the time since diagnosis was unknown. This data would have broadened the scope of the data as well as allow for further analysis. Greater details about participant demographics were collected later in the

program, but at several earlier events no data was collected regarding the number of survivors, family members, friends, stakeholder and health care providers.

The generalizability of the program's impact on the breast cancer survivor population in Saskatchewan is another limitation of the surveys. The population of individuals, who attended events, may have differed from those who did not attend and poses an additional limitation of representativeness of the Saskatchewan breast cancer survivor community in the results of this study. Although the participants who attended the program overall felt like the program made an impact in their survivorship journey, there were many more individuals who were not afforded the same opportunity. This could have been due to missed promotional opportunities, challenges partnering with other cancer organizations and collaborating with health regions. The women who were part of this study perhaps were those people who would have had an easier time finding the information, as they were able to find out about these events, which were not widely advertised. Furthermore, the Making Healthy Life Choices survey was double sided and the number of non-responses was much higher on questions on the back of the page, than on the front of the page. This misses a large number of respondents who may have added significant insight had they been made aware of the second half of the survey.

5.4 Recommendations

5.4.1 Recommendations for Survivorship Programs

It is well established that surviving cancer puts an individual at a higher risk of recurrence, developing secondary cancers, or associated illness. It is therefore in the best interest of health care professionals to encourage a healthy lifestyle and promote healthy behaviours to minimize such risks and potentially reduce an ongoing burden on the medical system. Since the need for such education may be beyond the capacity of the current health care system, grassroots, survivor driven initiatives offer ongoing positive messaging and support for individuals, once they graduate from treatment.

It is clear that women who have survived breast cancer continue to live with the long-term physical and mental health outcomes of their treatment, years after becoming cancer-free. They are never completely free of the emotional consequences. With independent groups implementing educational programs for survivors throughout the country, the acceptability,

impact or cost effectiveness of such initiatives are poorly represented in the literature. These efforts are largely uncoordinated and rely heavily on external funding and support.³⁷ However, there is significant pressure to “wrap up” programs within the funded fiscal year which leads to unmet deliverables and rushed events. It is important that organizations that rely on grants to run their programs remain realistic and flexible, as by the time the funding comes through, the timeframe is shorter than originally anticipated.¹¹

In order to achieve core public health functions, partnerships between community organizations and health promotion departments must be developed and sustained.⁴⁴ Future programs should first collaborate with health departments to develop a program in line with the priorities of the region, instead of parallel to provincially organized cancer care initiatives. In order to thwart a cool reception from Health Regions in the future, lobbying could be a way of gaining greater support and recognition of breast cancer as a chronic disease.

In the final report submitted by the SBCN to PHAC, they noted that in the future they would have first facilitated the education events in order to introduce the organization to the Health Regions and community members thereby increasing collaboration for events later in the program.¹¹ However, the Advisory Committee did prove to be invaluable by contributing their expertise to the program delivery and were also instrumental in connecting breast cancer service providers with survivors and building a sense of community among survivors in Saskatchewan.

5.4.2 Recommendations for Future Research

With the steady increase of survivors, there is a need for information well beyond treatment. After successful therapy many survivors become more health conscious and it is up to community-based health groups to take advantage of this “teachable moment” to encourage survivors to meaningfully change their health behaviours.⁹ In order to promote healthy lifestyle choices and behaviours among breast cancer survivors, understanding the meaning survivors place on health and wellness will optimize effectiveness. Currently little is known about perceived barriers and challenges to making these lifelong lifestyle modifications; which limits the effectiveness of current health promotion activities. Without additional evidence in the literature surrounding the motivations to support making healthy choices, it will be difficult for health promoters to develop effective programs, which provide survivors with the information needed to adopt these behaviours.

Limited research exists surrounding the actual implementation and maintenance of educational benefits. There remains an unknown relationship between meeting the needs of breast cancer survivors to facilitate behaviour change, and the integration of actual lifestyle changes. There may be an ongoing need for programming to be a catalyst in support of sustainable healthy behaviours. Although empowerment puts the ball in the survivor's court, it is up to the survivor whether they will play.

In the current program, many participants referred to the *photovoice* study conducted by Poudrier and Mac-Lean²³ in which twelve Aboriginal women in Saskatchewan participated. It is clear that that project made a lasting impact in giving voice to this underserved community, and the current program attempted to follow up on this success. Although the participation of minority groups in cancer survivorship programs is limited, developing culturally sensitive environments is essential for sustaining involvement.²² Additionally, as almost 25 percent of Canadian Aboriginals aged 15 and older have not completed high school it is essential that health information is available, accessible and understandable at all literacy levels.²⁴

The SBCN reached out not only to Aboriginal breast cancer survivors, but also acknowledged the different challenges faced at different stages throughout the lifespan, barriers in accessing information and service needs for rural residents. The needs of these underrepresented subgroups such as younger breast cancer survivors and rural breast cancer survivors need to be further researched. Additional research is needed to eliminate cultural disparities in the health care system in order to promote minority participation in cancer survivorship programs.²² One-size-fits-all survivorship programs overlook the diversity among Canadian breast cancer survivors and neglect the needs of unique cultural groups.

5.5 Conclusion

As previously stated, the purpose of the program implemented by the SBCN was to enhance, expand, and sustain the network with increased stakeholder involvement to promote healthy living by empowering communities, empowering breast cancer survivors, and by fostering the breast cancer community momentum and planning for the future. The four components of the program were implemented at various levels and included: enhancing information, education, networking and support.

Breast cancer is the second most prevalent cancer in women, and the amount of research conducted on this topic reflects its pervasiveness.¹⁸ The theme of survivorship is a key theme throughout the literature, although it seems to mean very different things in quantitative and qualitative studies. Survivorship research substantially contributes to breast cancer knowledge and highlights the ongoing challenges faced by survivors throughout their journey, and not just during their clinical treatment. There is an important need to bridge the gap between the clinical illness of cancer and the holistic cancer experience, and meet the needs of breast cancer survivors through an alliance between the health care system and community based organizations.

With regards to supporting the survivorship experience of women with breast cancer, the results of this evaluation reveal that the SBCN implemented the program as proposed. This was done despite unforeseen challenges, which necessitated slight alterations in the timing of events. Overall, the program was successful in meeting many of its goals. Survivors and stakeholders reported the importance of programs such as this one to bring everyone to the same table and to facilitate provider-client information sharing. Survivors can clarify their survivorship needs to providers and have direct input into future programming and services. The approach of the SBCN to bring all stakeholders together and to emphasize the survivorship issues makes it a unique program and one that would well serve the future of survivorship programs. However, the sustainability of these impacts is dependant on continuing human and financial resources on the ground.

6. EPILOGUE

Following the completion of *A Thinking, Learning and Caring Collaboration: Promoting a Healthy Lifestyle* the SBCN Program Coordinator retired. The sustainability of the Network is unknown to all those involved because of an inability to replace the coordinator, herself a breast cancer survivor, and follow through to obtain program funding. Though the Network partners may remain connected it is unlikely that without the constant collaboration orchestrated by a skilled coordinator that the formal Network will remain a priority.

In interviewing the Program Coordinator from the Canadian Cancer Society, the challenges of the Network without a Coordinator became evident. A proposal to move forward with a program addressing all cancers that affect women had been submitted in November 2009, with the current program already underway. In April 2010, the Public Health Agency of Canada [PHAC] replied with feedback including that they wanted to turn it into a two-year project, with a two-week deadline to resubmit the proposal with the requested revision. By this time, the SBCN Program Coordinator had already announced her retirement and without adequate support from the Advisory Committee, PHAC was advised of the circumstances and the proposal was withdrawn. Despite the hope to implement an enhanced, more encompassing program in the province, this was not possible in the absence of a dedicated champion.

Currently, the formal SBCN-orchestrated network does not exist; without the vision and commitment of the experienced and credible coordinator there may not be enough energy or conviction to re-submit a proposal and secure future funding. The reliance on a single person to coordinate the SBCN exposes the fragility of the entire network. This is consistent with the evaluation finding of the Canadian Breast Cancer Network's *Model for National Collaboration*. It may also bring into question the sustainability of the positive outcomes produced by the last ten years of programs.

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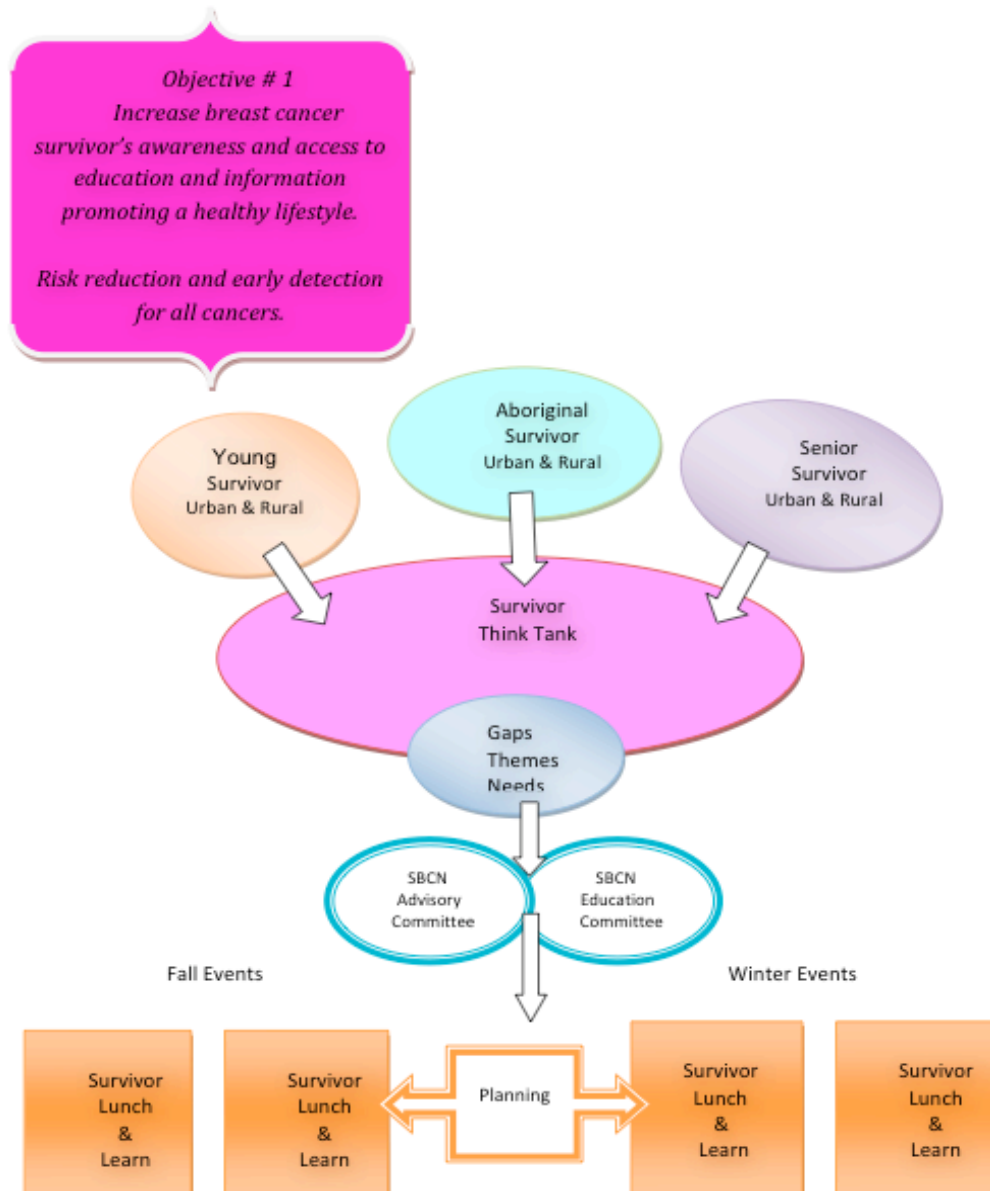
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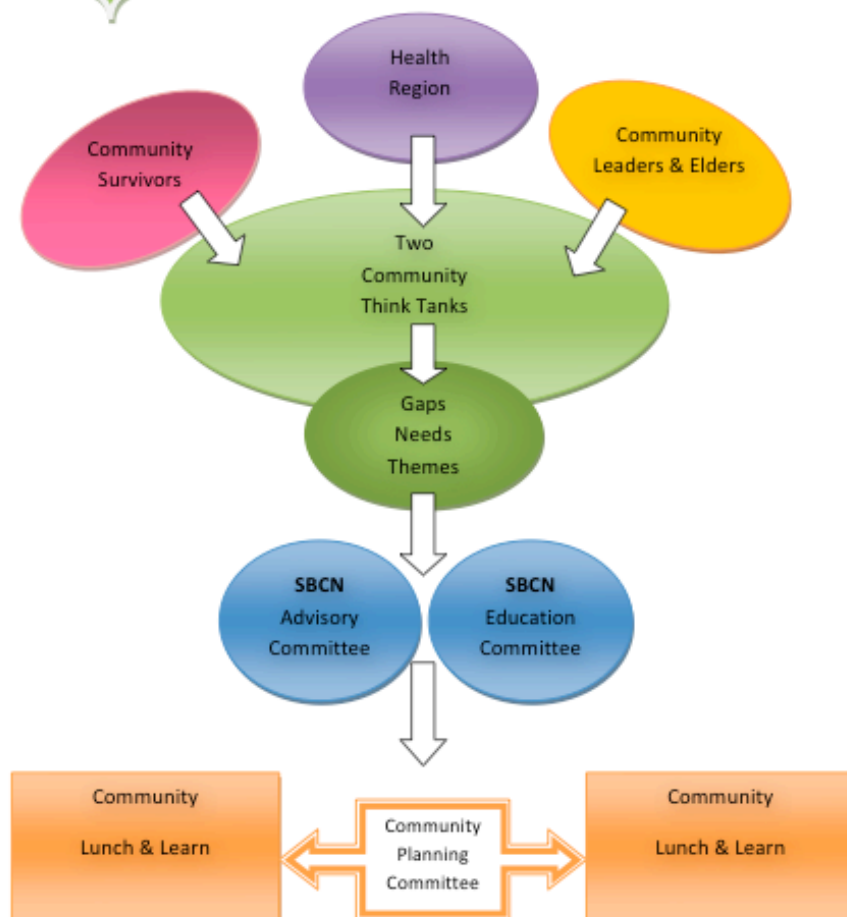
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APPENDIX A - Program Objectives



Objective #2
Increase public access and awareness to education & information promoting a healthy lifestyle leveraging the breast cancer community.

Risk reduction and early detection for all cancers.





APPENDIX B – Distribution List – Dissemination of Project Products and Findings

- Young women breast cancer survivors – local group
- Aboriginal breast cancer survivors
- Think Tank participants
- Saskatchewan Health Regions (12) – health promotion reps
- Aboriginal Health Organization
- Aboriginal Nurses Association of Canada
- Breast Cancer Action Nova Scotia
- Ovarian Cancer Canada
- Ovarian Cancer Support Groups (Saskatoon and Regina)
- Ovarian Cancer Awareness & Treatment in Saskatchewan
- Canadian Association of Retired Persons
- Canadian Breast Cancer Network, announcement of website and newsletter
- Canadian Cancer Action Network
- Canadian Medical Association
- Canadian Nurses Association – Journal
- Canadian Partnership Against Cancer
- Chronic Disease Prevention Alliance of Saskatchewan
- CIS – Canadian Cancer Society
- Diabetes Association of Canada
- First Nations Inuit Health Branch
- First Nations University of Canada
- Heart and Stroke Foundation
- Indigenous Women of Saskatchewan
- Journal of Aboriginal Health
- Métis National Council of Women
- National Council on Aging
- Ontario Breast Cancer Exchange Partnership
- Ovarian Cancer Canada
- Saskatchewan Cancer Action Network
- Saskatchewan Health Research Foundation
- Saskatchewan Registered Nurses Association
- Seniors Mechanism
- Teacher Federation Association,
- University of Saskatchewan Alumni Association
- Wellspring
- Willow
- YWCA –newsletter *Communique*

APPENDIX C – Survivor Think Tank Recommendation Document

What influences a breast cancer survivor adopting a healthy lifestyle after treatment? What are the barriers, and challenges? How, who and when? (Answers provided by senior, young, rural and urban breast cancer survivor participants)

Healing leads “living a healthy lifestyle”. “First things first healing/recovery needs to happen before you can even consider living a healthy lifestyle.”

A. Recovery – healing after treatment

The process of accessing support and information by the survivor from the beginning of her diagnosis affects her healing beyond breast cancer. A good foundation of support and assistance in accessing information creates a base for the survivor to continue with confidence and less sense of isolation and frustration.

Healing needs validation and understanding of the psychological and physical aspects of the survivor’s life beyond treatment by:

“Recovery from treatment – I need recognition and understanding from my friends, family and that I need time ... being done with treatment does not mean I have recovered or it is all behind me”

- Survivor (herself), Family, Friends, Community, Medical team and Breast cancer community

“I need to accept this myself that healing and recovery takes time...it is normal”.

Psychological and physical aspects of the survivor’s life beyond treatment identified by participants are:

“Feeling alone lack of validation of what a survivor feels and experiences beyond – “breast cancer”

Nothing is simple now “no simple answer” information that is required and delivered is more complex.

- Sense of being Overwhelmed
- Cognitive issues – “memory fog” requires energy and time to keep focused
- Having “cancer” - loneliness
- Isolation
- Loneliness – am I the only one that feels this way
- Disappointment – not being able to do the same activities or work that “I was able to do before my diagnosis”
- Sexual changes
- Emotions – Tears Anger, Sadness and Ambivalence
- Grieving
- Overwhelmed, Confusion
- Worthwhile factor – Am I Worthy, Anymore? I feel damaged.
- Life interrupted – that is how I feel now
- What is “Normal”
- Body image – accepting
- Recovery from treatment – recognized the need for healing time by friends, family and me.
- Need to prepare your answers for your children’s questions
- Coping with family and friends attitude about my breast cancer – Now
- “ how are you” “Is it gone”
- Pressure to be always “be positive”
- Getting through the day with the daily challenges drains any resolve.
- Decisions, decisions , daily decision on more decision – living healthy
- Being active, attempting to return to active lifestyle on the same terms as before diagnosis. *“Frustration of not being able to do the things I used to do”*
- My Sexuality
- Issues and concerns due treatment
- Due to menopause
- Unresolved issues
- Body image
 - How do I keep my daughter healthy my grandchildren?
 - How do I make sure the cancer doesn’t recur
 - “I have mets ... what does it matter?”

B. Health – my overall health

- Coping with multiple medical conditions at the same time.
- Side effects of treatment
- Side effect and reactions to medications
- Sleep patterns
- Menopause – symptoms and coping - young*
- Fatigue – identified as a influencing factor but strongly identified by the young participants
- Physical capabilities - side effects, other health problems and metastases
- Compounds the challenge of living well
- Recovery from treatment consideration
- Coping with allergies that affect: Physical capabilities, access to facilities, access to information that addresses allergy issues to assist with my diet and my environment

C. Support systems

- No support systems – beyond active treatment
- Not knowing who can help me become healthier?
- Needs consideration and respect often not in sync when it comes to giving or receiving support. Timing is everything.
- Lack of support from spouse, family and friends
- Spirituality – can provide a sense of comfort, support and motivation

Lifestyle of spouse, family and friends

- Not active and with poor food choices and habits is negative support.
- Active with good food choices and habits is a positive support and benefit.
- A walking partner is a real bonus

D. Responsibility

- Giving my health and myself the priority it deserves and needs.
- Family and friends - needs
- Career and employment
- Community role – volunteer (rural) .The rural community relies on volunteers
- Women as mothers, daughters their roles and expectations
- Family & friends issues and demands – their schedules and activities
- Crisis & illness me, family and friends requires time and finances
- Sandwich generation a serious demand and responsibility as the population ages. Young participants strongly identified this as a challenge and demanding of their time influencing their own lifestyle and healthy choices

E. Motivation is major challenge in adopting a healthy lifestyle

- How do I stay motivated – “I need a buddy”?
- Motivation to change
- Crisis - sidelines our motivation to stick to making healthy choices – hard to get back on track
- Family & friends illness – sidetracks good intentions, motivation, plans, interferes with healthy choices and well-being
- I love my comfort food too much to change
- Doing instead of “talking” - support groups would help
- Will power, habits

F. Weather

- Winter is challenge for all in this province regarding physical activity
- Rural – few indoor facilities to have walking programs or opportunities such as mall walking
- Senior – fear of slipping on ice and driving in winter

- Rural – winter driving presents an obstacle in timing and access to services and information - determines participation at workshops and education sessions.
- Young – not a strong opinion on this just in agreement as their roles increase to provide service to their young and older family members and friends. Older family and friends rely on young rural community members to provide transportation during the winter months.

G. Access to resources: services, facilities

- Which in many cases in rural areas are non existent
- Scent free and allergy respectful limits access
- Challenge for rural residents beyond that of the urban resident.
 - Increasing challenge for senior
 - Young reported that time affected their access to resources more than finances you still have to know about the resources and that is a common challenge for us all... young, senior, rural and urban.

H. Financial and economic consideration affects our balancing act (healthy lifestyle)

- | | |
|--|--|
| <ul style="list-style-type: none"> • Coping with stress • Accessing resources • Access to transportation • Buying foods • Access to fresh foods by rural and aboriginal • Seniors often have a low income • Social activities • Relationships – meeting friends, getting out • Worry about financial situation – increases stress • Demand on finances increased for rural - access to activities (transportation) cost of produce and healthy food. | <ul style="list-style-type: none"> • Cost of special products • Supplements • Designed to be more respectful of allergy sensitivities • Food substitutions to accommodate food allergies such as lactose intolerance, gluten free • Limitation of financial security results causes: (young, senior and rural) • Depression • Barriers to accessing information (can't attend education session , have to work , can't afford transportation, can't afford baby sitter, purchasing fresh foods, produce |
|--|--|

I. Time

- | | |
|--|--|
| <ul style="list-style-type: none"> • Pressure to be “Super Woman” or Super Mom” • Challenge to find time “For me” • To access education and information • Planning • Include my exercise, my nutrition • For balance | <ul style="list-style-type: none"> • Shift work • Time frame – need time to heal – physically and emotionally • Need time to recover from treatment – then look at challenges to making healthy choices on own terms. |
|--|--|

J. Transportation for the rural senior and Aboriginal it requires consideration of:

- Time
- Weather
- Financial
- Health traveling requires being well enough

K. Alone

- Senior – I live alone – it is up to me for everything
- Young - Am I the only one that feels like this
- Rural – we are on our own – it is different when you have to drive to everything and everything is in the city
- Aboriginal – I didn't know anyone from my culture who was going through this ... I just wanted to see a brown face ... know that they are okay they got through this.

L. Isolation – many aspects of isolation

- All participants expressed tired of accessing information on their own. “Accessing information on websites – frustrating, time consuming, scary, confusing and overwhelming.” “I have done enough, I just can’t anymore”. “I need to listen and discuss, not read and search and surf”.
- Diagnosis and prognosis
- Living alone
- Lack of support system
- Financial circumstances
- Rural resident
- Accessing information on your own
- Accessing information on the web, books and pamphlets - senior issue not entirely as young survivors identified this a growing issue
- Young survivors – the overload they dealt with in finding info their diagnosis and treatment decisions has left them overwhelmed and to the point of not wanting to do any more accessing information – needs to an easier way too much on our own!!

M. Accessing healthy nutrition

Poverty - no money ... just filling the belly is a priority ... eating fruit and vegetables is expensive

- Consulting a dietician or nutritionist
- Confusion about foods – should I include flax, soy in my diet?
- What are healthy foods?
- What about anti oxidants
- What about new buzz word or health product “pomegranate”
- Which yogurt is best?
- Living alone and cooking for one
- Cooking for a family and juggling the likes and dislikes
- The lost art of cooking – expressed by young participants
- The lost art of eating healthy – or knowing how to eat healthy. “ We assume too much”
- Family preferences
- Reluctance or refusal of family to consider wish to use organic products
- Information to support – pros to using organic products.

N. Accessing Information Issues

“I spent so much time and energy searching websites and looking for resources from diagnosis through treatment, now that I am done ... I am just too tired and overwhelmed to even look for more information on how to live healthy”.

“I need a break ... but then I panic and think what should I be doing or am I doing the right thing to prevent a recurrence”.

- Timing of information access
 - Sometimes to overwhelming
 - Need it when I leave the clinic
 - Need information repeated, reminder after treatment a refresher.
 - Information needs of the survivor do not end at end of treatment!! We need updates and current information.
- Lack of information from medical team.
- Confusion - So many question and no answers
- Lack of information geared to breast cancer survivor after treatment need to be increases as well as enhanced awareness and access to this information
- Limitation of access to technology – high-speed Internet access.
 - Some websites require high speed Internet access – this is a particular barrier or challenge identified by senior and the rural survivor.
- Understanding technology, skill to use computer - identified more specific to senior women but then on reflection identified as a financial factor as well)

- Understanding what I need to know.
 - Having the information that creates confidence in me to feel that I am well informed to
- Change in expectations of ourselves – reading labels, accessing information is not routine for many seniors – this requires adjustment of action and habit.
- Need information that looks at my total health history and helps me develop a health plan for a healthy life
- Access and awareness of resources paramount to being informed and making the right choices for a healthy lifestyle.
- Unreliable information & contradictory information
 - How do we know if it is creditable information
- Advertising messaging confusing
- Understanding – huge influence
 - What I need to know
 - Website information
 - Research information
- Confusion – what and who has or is giving the right information
 - Media adds to this confusion
 - Advertising claims also cause confusion

O. Information a survivor wants

- Research Information
- Need for more individual and specific information tailored to young, senior and rural survivors. Young needs more information that is relevant to going back to work, child care and fertility
- Need someone to guide us to resources.
- Need connection to experts.
- Access to the most up to date and comprehensive research reviews and recommendations
- Access to info on side effect and reactions to medications and treatment medications and the future implications.
- What does estrogens positive mean? (Asked by senior survivor)
- Understanding – huge influence
 - What I need to know
 - Website information
 - Research information
- Media reports about research have the potential to cause concern, fear and misunderstanding - are they accurate, reliable, and helpful?
- There is a need for knowledge transfer! We need research reports (findings) translated, in and shared in an understanding way.
- Lack of comprehensive knowledge transfer strategies by the research community that focuses on survivors:
 - Access
 - Awareness
 - Understanding

Understanding about organic foods, natural products and supplements

- Are natural meds/supplements healthier?
- What is the right natural product?
- What is wrong natural product?
- How do I interpret advertising messages?
- Natural products – will they help, and for whom?
- What if I don't use natural products? Will that hurt my recovery?
- What info do you trust regarding products, natural, organic etc.
 - Natural companies, brand claims?

Nutrition

- | | |
|----------------------------|--|
| • What are healthy foods? | • What about new buzz word or health product “pomegranate” |
| • What about anti oxidants | • Which yogurt is best? |

- What is the best diet?
- Should I include flax, soy in my diet?
- Need information that looks at my total health history and helps me develop a health plan for a healthy life

Environmental

- Reliable information without the overzealous confusing declarations that make me afraid
- Information that helps me to see what I can do or change.
- I don't need frightening information that – IT caused my cancer
- I need sensible and calm information about what are the right healthy choices in MY environment.
- Information needs to be: Understandable
- We need reminders about the healthy lifestyle and our environment - more information and increased access and awareness`

Lymphedema

- Living with Lymphedema
- Fear of Lymphedema
- Coping and understanding
- Lack of information on Lymphedema
- Understanding Lymphedema

Recommendation by: Think Tank Fall 2009 - -participants

Participants in consensus summed up with the recommendation that all breast cancer survivors in Saskatchewan need a comprehensive, collaboratively developed and facilitated rehabilitation program. Programs to look at, as models are cardiac rehabilitation and the Live Well with Chronic Conditions program.

APPENDIX D – Aboriginal Survivor Think Tank Recommendation Document

Aboriginal participants at this Think Tank supported all the documented issues and concerns expressed by the breast cancer survivors at the Fall 2009 Survivor Think Tank with the addition of a strong recommendation that more effort and emphasis needs to be adopted and initiated in Saskatchewan to assist Aboriginal cancer survivors to become more:

- Connected to other Aboriginal cancer survivors “I wanted to talk to someone who understood and was from my culture”, “I wanted to see a brown face”.
- Informed and supported

To do this the Aboriginal cancer survivor’s concerns and issues need to be validated and addressed. In particular the Aboriginal Breast Cancer Survivor indicated the following:

- Adopting a healthy lifestyle is so far removed from most of our daily lives when we face issues of poverty, addiction and housing.
- We need help to teach our own - we listen to someone with a brown face
- We need a program that has Aboriginal cancer survivors telling their stories in our communities along with a message of learning about cancer. What you should know and what you should do.
- We need information and education that respects our culture.
- Eating healthy for many of us means being able to just put food on the table
- As a survivor I want to tell women that you can be diagnosed early and you can cope with chemotherapy... I did.
- Grief is our barrier ... for us how do we carry on when we have so much sadness and grief ... cancer is just one more thing it shuts your mind off why bother ... it just too much.
- We don’t need lessons of preaching we need understanding.
- Telling our stories, talking like today is the best it helps our healing.
- We need a different way to have information get out ... no one wants to talk about cancer. It is a scary word.
- Videos and posters that have our face and our stories are what we need
- Aboriginal cancer survivors traveling to our communities saying look at me I am okay... don’t be afraid. Will help with encouraging early diagnosis.

APPENDIX E – Saskatchewan Breast Cancer Network Contact Consent Form

I, _____ (print first & last name) acknowledge and agree that I grant permission to the Saskatchewan Breast Cancer Network and contact me for the purposes of evaluating the 2009-1010 SBCN Project. This may be in the form of a questionnaire or a telephone interview. I understand that at any time I may withdraw my participation.

Signature: _____

Date: _____

Our commitment to your privacy

Confidentiality is fundamental to our services. Your personal information is kept confidential.

APPENDIX F – Transcript Release Form

I, _____, have reviewed the complete transcript of my personal interview in this study, and have been provided with the opportunity to add, alter, and delete information from the transcript as appropriate. I acknowledge that the transcript accurately reflects what I said in my personal interview with Ellie Adler. I hereby authorize the release of this transcript to Ellie Adler to be used in the manner described in the Consent Form. I have received a copy of this Transcript Release Form for my own records.

Name of Participant

Date

Signature of Participant

Signature of researcher

APPENDIX G – Study Ethics Approval



UNIVERSITY OF
SASKATCHEWAN

Behavioural Research Ethics Board (Beh-REB)

Certificate of Approval

PRINCIPAL INVESTIGATOR
Anne Leis

DEPARTMENT
Community Health and Epidemiology

BEH#
10-129

INSTITUTION(S) WHERE RESEARCH WILL BE CONDUCTED

STUDENT RESEARCHERS
Ellie Adler

SPONSOR
UNFUNDED

TITLE
Evaluation of "A Thinking, Learning and Caring Collaboration: Promoting a Healthy Lifestyle" Project

ORIGINAL REVIEW DATE
17-May-2010

APPROVAL ON
14-Jun-2010

APPROVAL OF:
Ethics Application
Consent Protocol

EXPIRY DATE
14-Jun-2011

Full Board Meeting ☐

Date of Full Board Meeting:

Delegated Review ☒

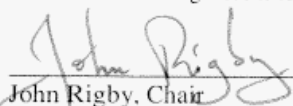
CERTIFICATION

The University of Saskatchewan Behavioural Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol or consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

ONGOING REVIEW REQUIREMENTS

In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions: http://www.usask.ca/research/ethics_review/


John Rigby, Chair
University of Saskatchewan
Behavioural Research Ethics Board

Please send all correspondence to:

Research Ethics Office
University of Saskatchewan
Box 5000 RPO University, 1602-110 Gymnasium Place
Saskatoon SK S7N 4J8

APPENDIX H – Advisory Committee Members Consent Form

Researcher:

Ellie Adler
Department of Community Health &
Epidemiology
College of Medicine, University of
Saskatchewan
Saskatoon, Saskatchewan, Canada
E-mail: ela043@mail.usask.ca

Research Supervisor:

Dr. Anne Leis
Department of Community Health &
Epidemiology,
College of Medicine, University of
Saskatchewan
Saskatoon, Saskatchewan, Canada
E-mail: anneleis@usask.ca

Purpose and Procedure: The purpose of the current study is to evaluate the effectiveness of a networking program run by the SBCN towards improving access to health information and understanding the unique challenges and perceived barriers of urban, rural, young, and older breast cancer survivors towards making healthy lifestyle changes. You are invited to attend one interview session either in person or by phone, which will last approximately one hour. The information collected from this interview will be used as part of the requirements of a master's thesis, and they may be published and presented publicly.

Potential Benefits and Risks: There are no known risks to your participation in this study, and there may not be any direct benefits. The information you provide will help to give me a greater understanding of the roles of individuals and organizations in the Saskatchewan breast cancer survivor community. With the information obtained from your interview, I hope to be able to better evaluate whether the goals of the program implemented by the Saskatchewan Breast Cancer Network (SBCN) have been met. Participating in this study gives you an opportunity to share your important role as a key stakeholder and as a member of the advisory committee and add your personal experiences and perspective in the growing body of research on breast cancer survivorship.

If you desire, you will be given the opportunity to review the transcript from our interview. You may clarify, alter or delete it as you see fit. Direct quotations may be used if they do not breach confidentiality or identify you in any way. All other data will be presented in an aggregated manner. However, it is important to note that as a member of a small advisory committee, with a publicized role in the program, you may be identifiable even when all other measures to protect your identity are used. As a result, it may be difficult to ensure statements made in your interview are not easily attributed to you as an individual member of the advisory committee.

Privacy and Storage of Data: All the tape recordings, notes and transcript from your interviews will be kept private and stored in a secure location. Although I may share information with my research committee, I am the only person who will hear your recordings. The information that you give will be saved in the form of transcripts, and notes in a locked filing cabinet or room by Dr. Anne Leis at the University of Saskatchewan for at least five years. When they are no longer needed, they will be destroyed. All audiotapes will be stored in a locked filing cabinet by Dr. Anne Leis at the University of Saskatchewan for at least 5 years after the study is completed and then destroyed.

Right to Withdraw: Your participation is voluntary, and you can answer only those questions that you are comfortable with. You may also request that the recording device be turned off at any time. There is no guarantee that you will personally benefit from your involvement. The information that is shared will be held in strict confidence and discussed only with the research team. You may withdraw from the research project for any reason, at any time, without penalty of any sort and will not affect any relationships with the SBCN or the breast cancer community in Saskatchewan. If you withdraw from the research project at any time, any data that you have contributed will be destroyed.

Questions: If you have any questions concerning the research project, please feel free to ask at any point; you are also free to contact the researchers at the numbers provided if you have other questions. This research project has been approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board on June 14, 2010. Any questions regarding your rights as a participant may be addressed to that committee through the Ethics Office (306-966-2084). Out of town participants may call collect.

How your information will be used:

By making a mark inside the box, you are signifying that we have permission to use your information the way it is described. You can always make changes to how your information will be used as you see fit.

I would like to use (check one):

- ☐ my full name
☐ my first name only
☐ a pseudonym _____

when my information is reported.

Do you wish to review your transcript once it has been transcribed by the researcher? (check one)

- ☐ no ☐ yes

Consent to participate: *I have read and understood the description provided. I have had an opportunity to ask questions and my questions have been answered. I consent to participate in this research project, understanding that I may withdraw my consent at any time. A copy of this consent has been given to me for my records.*

Signature of Participant

Date

Signature of Researcher

Date

APPENDIX I – Breast Cancer Survivors Consent Form

Researcher:

Ellie Adler
Department of Community Health &
Epidemiology,
College of Medicine, University of
Saskatchewan
Saskatoon, Saskatchewan, Canada
E-mail: ela043@mail.usask.ca

Research Supervisor:

Dr. Anne Leis
Department of Community Health &
Epidemiology,
College of Medicine, University of
Saskatchewan
Saskatoon, Saskatchewan, Canada
E-mail: anneleis@usask.ca

Purpose and Procedure: The purpose of the current study is to evaluate the effectiveness of a networking program run by the SBCN towards improving access to health information and understanding the unique challenges and perceived barriers of urban, rural, young, and older breast cancer survivors towards making healthy lifestyle changes. You are invited to attend one interview session either in person or by phone, which will last approximately one hour. The information collected from this interview will be used as part of the requirements of a master's thesis, and they may be published and presented publicly.

Potential Benefits and Risks: There are no known risks to your participation in this study, and there may not be any direct benefits. The information you provide will help to give me a greater understanding of the roles of individuals and organizations in the Saskatchewan breast cancer survivor community. With the information obtained from your interview, I hope to be able to better evaluate whether the goals of the program implemented by the Saskatchewan Breast Cancer Network (SBCN) have been met. Participating in this study gives you an opportunity to share your important role as a breast cancer survivor in the community and add your personal experiences and perspective in the growing body of research on breast cancer survivorship.

If you desire, you will be given the opportunity to review the transcript from our interview. You may clarify, alter or delete it as you see fit. Direct quotations may be used if they not breach confidentiality or identify you in any way. All other data will be presented in an aggregated manner. However, it is important to note that as breast cancer survivor in the province of Saskatchewan, there is a possibility that you may be identifiable even when all other measures to protect your identity are used. As a result, it may be difficult to ensure statements made in your interview are not easily attributed to you.

Privacy and Storage of Data: All the tape recordings, notes and transcript from your interviews will be kept private and stored in a secure location. Although I may share information with my research committee, I am the only person who will hear your recordings. The information that you give will be saved in the form of transcripts, and notes in a locked filing cabinet or room by Dr. Anne Leis at the University of Saskatchewan for at least five years. When they are no longer needed, they will be destroyed. All audiotapes will be stored in a locked filing cabinet by Dr. Anne Leis at the University of Saskatchewan for at least 5 years after the study is completed and then destroyed.

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Questions: If you have any questions concerning the research project, please feel free to ask at any point; you are also free to contact the researchers at the numbers provided if you have other questions. This research project has been approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board on June 14, 2010. Any questions regarding your rights as a participant may be addressed to that committee through the Ethics Office (306-966-2084). Out of town participants may call collect.

How your information will be used:

By making a mark inside the box, you are signifying that we have permission to use your information the way it is described. You can always make changes to how your information will be used as you see fit.

I would like to use (check one):

- ☐ my full name
☐ my first name only
☐ a pseudonym _____

when my information is reported.

Do you wish to review your transcript once it has been transcribed by the researcher? (check one)

- ☐ no ☐ yes

Consent to participate: *I have read and understood the description provided. I have had an opportunity to ask questions and my questions have been answered. I consent to participate in this research project, understanding that I may withdraw my consent at any time. A copy of this consent has been given to me for my records.*

Signature of Participant

Date

Signature of Researcher

Date